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ABSTRACT

This manual provides information to assist individuals in working together more effectively to provide comprehensive services and improve outcomes for children with special health care needs. The manual emphasizes the need for a union of services that places the child and family at the center and exists to provide educational, medical/health, and human services. The manual also emphasizes that promoting such services requires collaboration and commitment from parents, health professionals, educators, administrators, state agencies, elected officials, and concerned citizens. The objectives of the partnership-building process include: (1) strengthen commitment to the developmentand expansion of family-centered, community-based, coordinated services for children with special health care needs; (2) design services that promote transition from childhood to full functional adulthood; (3) define leadership roles; (4) provide training and support to facilitate the development of services; and (5) facilitate and support community level teamwork. Chapters of the manual provide information on the components of a system of services, types of support needed, transition and related issues, parent's role, health and medical services, nurse's role, early and periodic screening, educator's role, and public education laws. The manual concludes with a list of educational terminology and medical terminology. Contains 34 references. (JDD)

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Building Partnerships for Special Needs Children

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A Parent and Provider Resource

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FOR THE CHILDREN
BUILDING PARTNERSHIPS FOR SPECIAL NEEDS CHILDREN

a special project of

CHILDREN'S HEALTH SERVICES

Division of Public Health
Wyoming Department of Health

***Children's Health Services** is responsible for assuring that services are provided for children with special health care needs in Wyoming. **Children's Health Services** implemented **Partnerships for Special Needs Children** to strengthen our commitment to develop a family-centered, community-based, coordinated system of services that will serve all children with special health care needs in Wyoming.*

Written and compiled by Deborah J Barnes, RN,BS

A special thanks to those parents and providers who shared their knowledge, experience and time to make completion of this manual possible.

December 1993

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PARTNERSHIPS FOR SPECIAL NEEDS CHILDREN

Objectives:

1. *Strengthen commitment to the development and expansion of family-centered, community-based, coordinated services for children with special health care needs.*

2. *Design services for children with special health care needs that promote transition from childhood to full functional adulthood.*

3. *Define leadership roles in the emergence of statewide community-based service systems for children with special health care needs.*

4. *Provide training and support to facilitate the development of a culturally sensitive, family-centered, community-based, coordinated system of services for children with special health care needs.*

5. *Facilitate and support community level teamwork.*

INTRODUCTION

All children require access to medical, health and educational services in order to grow and develop to their maximum potential. The demand for these services continues to increase, while access to and funding for services continues to decrease. This is a growing concern for all children but is especially true for children with special health care needs. Children with special health care needs includes a broad spectrum of children with health problems requiring something beyond routine and basic care. This care involves a comprehensive range of services designed to meet the changing needs of the child and family. These services must support the child's continued growth and development and assist the child in reaching his/her full potential.

To adequately meet the needs of this diverse group of children and their families requires that we reevaluate the way in which we currently provide services. The health care system and patterns of service delivery are currently changing, with new roles emerging for parents and providers. In 1987 the Surgeon General of the United States called for the establishment of family-centered, community-based, coordinated systems of care to more adequately meet the needs of children with special health care needs and their families. Recent legislative mandates place increasing responsibility upon states and communities to develop such systems and to ensure that coordination is enhanced among community and state agencies and individual service providers.

Promoting family-centered, community-based, coordinated systems of services requires collaboration and commitment from us all. This includes parents, health professionals, educators, administrators, state agencies, elected officials at all levels, and concerned citizens. We all have an interest in the delivery of quality health care to children.

***Children's Health Services** implemented **Partnerships for Special Needs Children** recognizing the need to facilitate the development of community-based systems of services that are family-centered and coordinated. The focus of this project is to furnish information to providers (including parents) and to assist them in learning to function as members of a community based team.*

This notebook summarizes information for all members of the team. You will gain a clearer understanding of the role of other members of the team; your contribution to the team; the challenges that families face; terminology used by other providers; the broad scope of the public education laws; and what you can do to support families and foster their growth and independence.

We share a common concern for the future health and well being of all our children. We need to become effective advocates for children. This notebook shows you how. You will learn that it can be as simple as making a referral or phone call, asking the family what they want for their child, attending a meeting, providing information or asking questions. All of these little things add up to make a big difference in the future of the family and the child with special health care needs.

WHY USE THIS NOTEBOOK

Compare yourself to a classroom teacher, regardless of your current occupation. Through your training and experience you have developed a level of confidence and comfort in the classroom. You know what is expected of you and what to expect from others that you work with on a daily basis. For the most part you feel you are addressing the needs of your students and meeting personal goals.

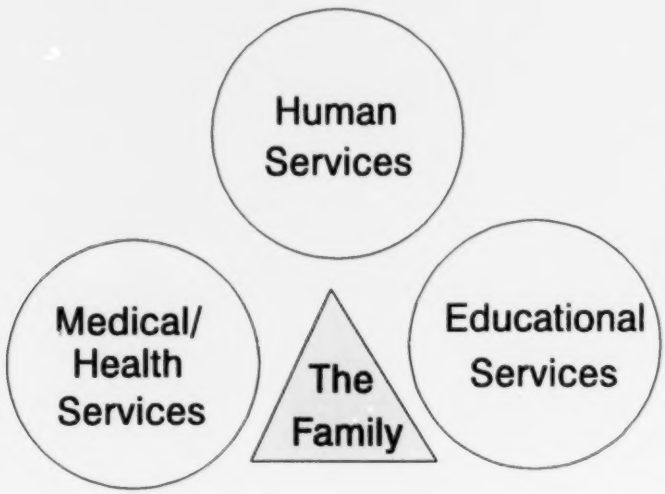
What happens when a student enters your classroom and shatters that confidence? This may be a child with a chronic illness or disability, a child with a learning disability or behavior problem, or even more challenging a child who previously has not been identified as having special needs. Suddenly it becomes apparent to you that you cannot meet this child's educational needs without also addressing medical and social needs. As a classroom teacher do you feel there are avenues open to you to help this child and family? Do you have access to a system of care that integrates health, medical, educational, social, and family issues? If the answer is no, what will it take to develop such a system? What can you as an individual do to make such a system available for any child?

Goal: To learn to work together more effectively to provide comprehensive services and improve outcomes for children with special health care needs.

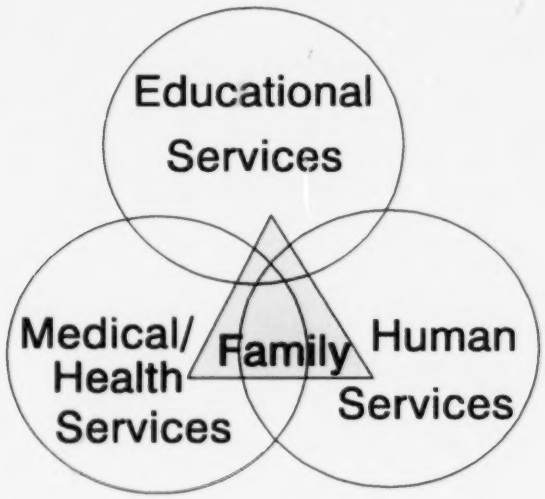
Method: The notebook provides concise information to assist anyone in accomplishing this goal.

Services are currently organized so that they resemble the following diagram. In your own circle you know the rules, the language, what is expected of you, and what to expect from others.

Do you ever risk leaving your circle? What information and skills do you need to enter other circles? Do you feel you will be welcomed?



We need to learn to cross the boundaries that currently exist and cause us to look at the child with special health care needs as having separate and independent health, medical, educational, psychosocial and family needs. Crossing the boundaries should not be considered an intrusion but a union. A union that places the child and family at the center and exists in order to provide comprehensive and coordinated services. The following diagram illustrates this.



This manual is unique, in the fact, that it does not focus on the needs and interests of one particular group. It is written for any individual. Although sections of this manual do address specific providers, these sections are useful to anyone. They will help you gain a clearer understanding of the roles and expectations of others, and to broaden your perspectives. Using this manual can be compared to putting together the pieces of a puzzle. Alone the pieces don't mean much, but once the puzzle is put together we all see the same picture.

10 to 15% of all children in the United States are born with a chronic or disabling condition. Of those, nearly one third have disabilities which limit activities of daily living. Over the past 20 years improvements in neonatal life support technologies and medical/surgical interventions has lead to a decrease in early childhood mortality. Over 85% of children born with chronic conditions and disabilities will survive until at least the age of 20. All of these factors have a major impact on the services we provide. How do we provide the medical,social, developmental, educational and vocational support these youth and their families require?

It is important that we all understand that children with special health care needs are "just like" other children. All children require a loving nurturing environment, access to medical care, health guidance, educational and vocational opportunities, social interactions, and peer group support to grow and develop to their maximum potential. The child with special needs requires these same things, but it takes more planning and intervention to accomplish them. Every family creates a mini-system of care for each child, the system of care for the child with special health care needs is just more complex. Organizing a community-based system of services that is family-centered and coordinated will assist families and providers in providing the best possible care for all children.

What Is A System of Services?

The dictionary defines a system as an interdependent group or network organized to serve a common purpose. Words synonymous with system include plan, order, network, pattern, practice, process. Do we currently have a plan or process for meeting the comprehensive needs of children with special health care needs and their families or do we have fragmentation and territorialism? Can we improve services and outcomes by making a commitment to develop a system?

A system is not a rigid organization that requires funding, office space, or salaried employees. A system is dependent upon information sharing, cooperation, and commitment.

Elements of the Service System for Children With Special Health Care Needs

1. The system should serve a broad population of children who have health problems requiring something beyond routine and basic care.

- children with disabilities and handicapping conditions
- children with chronic illnesses and conditions
- children with health related educational problems
- children with health related behavior problems
- children at risk for any of the above
- the families of children with special health care needs

2. The system assures that comprehensive and coordinated services are available and accessible to the child and family. This includes:

- medical services (primary and specialty care)
- early intervention services
- educational services
- vocational services
- mental health services
- social services
- recreational services
- financial services
- family support services (parent to parent support and respite care)

3. The system provides culturally sensitive, family-centered, community-based, and coordinated services.

-families work in partnership with professionals
-services are provided within or near the child's home community whenever possible

Culturally Sensitive Services

- recognizes the cultural diversity of families who have children with special health care needs
- acknowledges and honors the cultural traditions, values and the diversity of families
- recognizes that perceptions about chronic illness, disability, health and ability are influenced by culture
- adapts practice skills to fit the family's cultural context

Developing a system that serves children with special health care needs involves working with families from diverse backgrounds and cultures. Providers need to recognize that their personal prejudices, beliefs and behaviors may not fit with the family's beliefs. Acknowledging the diversity of families is an important responsibility for providers. Providers need to understand that past experiences and cultural traditions affect the families thinking and actions regarding their child's care.

Families often face the challenge of working with providers who do not understand or support their language, beliefs, traditions or ways of life. When providers demonstrate to the family a willingness to be respectful, the family can show professionals how to provide services and support in a way that is acceptable and meets the family's needs.

Family-Centered Services

- recognizes the family as the constant in the child's life
- promotes parent-professional collaboration at all levels
- shares complete and unbiased information with parents in a consistent and supportive manner
- recognizes family strengths and individuality, and respects different methods of coping
- is flexible, accessible and responsive to family needs
- addresses developmental concerns as the child grows to adulthood
- facilitates family to family support and networking

The family must be central to any system of care. Services and providers change with time as the child's needs change. Providers must acknowledge the family as the constant in the child's life and essential to the outcome of care. Families must be recognized as the experts on their child's strengths and weaknesses, the challenges of providing care and the needs of others in the family. The family must be allowed to work in partnership with the professionals caring for their child. All providers have it in their power to provide family-centered care, it is the first step in developing a system of services for children with special health care needs.

The CHALLENGE

the child and family must

learn to make successful

adaptations and adjustments

We can help families meet this CHALLENGE

by the way we organize services

Community-Based Services

- provides services within or near the child's home community
- promotes continuity of care and follow-up
- supports families so they can care for their children at home whenever possible
- promotes normal patterns of living for the child and family
- provides referral outside the community as needed (with information sharing back to the local community)
- assures that services are developed and supported by the community

Since Wyoming is a vast and sparsely populated state some of the services required by children with special health care needs may not be available in the child's home community or even within the state. Families may need to travel up to 100 miles or more to obtain necessary services. This makes planning for services and support of the family at the community level even more critical. Neighboring communities may find it helpful to pool resources, develop referral networks with surrounding communities, and organize and support services on a regional basis. These efforts will improve access to and availability of services for families.

Coordinated Services

- provides multiple services from different providers in a complementary, consistent and timely manner
- allows for efficient use of limited resources
- prevents delays, overlaps and gaps in services
- requires teamwork

Children with special health care needs and their families generally require multiple services from different providers. Gaps and duplications in services result because many public and private programs serving these children and their families have differing mandates, differing eligibility requirements, and inconsistent policies.

Coordinating services is difficult because it requires cooperation and collaboration between a variety of providers and agencies. Since cooperation and collaboration is voluntary it can be difficult to sustain. Coordinated care is possible if all providers, including parents, learn to work together as members of a team.

Family-Centered, Community-Based, Coordinated Care benefits the child and family!

The Child...

- grows and develops toward independent adulthood
- develops a positive self-image
- is knowledgeable about his/her illness or disability

The Family...

- understands the child's diagnosis, prognosis, and treatment plan
- feels comfortable caring for the child
- effectively uses a range of resources
- maintains social and financial stability

Family-centered, community-based, coordinated care allows the child with a complex disease, chronic condition or disability to participate as fully as possible in all aspects of family and community life and to realize his/her full potential.

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COLLABORATION

The national movement to provide family-centered, community-based, coordinated care is an outgrowth of collaboration between families and professionals. Family-centered, community-based, coordinated care not only describes what is missing from our current system of care, it also provides a blueprint for designing a better system of care.

Although collaboration is accepted as a "good thing" there is much confusion over what it is and how to achieve it.

We should not associate collaboration with power sharing or giving up power, instead we must learn to associate collaboration with empowerment. We must be careful not to continue to think and do things as usual but just call it by a new name. True collaboration requires a commitment from families, professionals, agencies, communities, federal and state administrators and others.

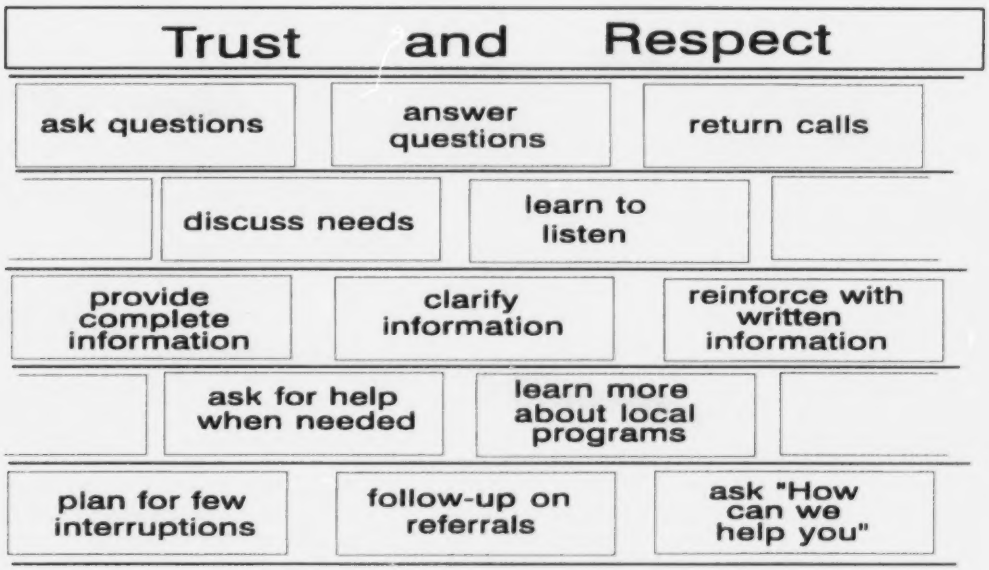
The most common barriers to successful collaboration are poor communication, lack of mutual trust and respect, unreasonable expectations, and a lack of knowledge on how to work together. Successful collaboration requires that both parents and professionals realize that neither can do it alone, that each needs the other. Parents need professionals, professionals need parents, and the child needs both.

Successful Family/Professional Collaboration

1. Promotes a relationship in which family members and professionals work together to ensure the best services for the child and family
   - professionals must develop the skills to treat parents as partners
   - professionals must feel comfortable as consultants to parents
   - parents must develop the skills to treat professionals as partners
   - parents must feel comfortable as consultants to professionals
2. Recognizes and respects the knowledge, skills, and experience that families and professionals bring to the relationship
3. Is based on trust and open communication
   - one of the most important strengths that anyone can bring to the relationship is the ability to listen
   - parents and professionals need to be able to trust each other to do the best they can, to ask for help when needed, and to be able to say "I don't know"
   - parents need to be in charge of making the major decisions for their child's care
   - professionals need to provide information to parents so parents will know what their choices are and what it will mean for their child
4. Creates an atmosphere in which the cultural traditions, values, and diversity of families are acknowledged and honored
5. Recognizes that negotiation is essential in a collaborative relationship
   - team members express priorities, preferences, and options
   - negotiation focuses on meeting the needs of the child and family and not on differences among individuals
   - flexibility is essential
   - negotiation does not end with the development of services
6. Requires a commitment from families, professionals, and communities to meet the needs of children with special health care needs and their families

HOW DO WE BEGIN TO COLLABORATE?

Collaborative relationships just don't happen, they are built. Your individual actions provide the foundation that supports trust and respect. Collaboration is built upon trust and respect.



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WHY PARTICIPATE ON A COMMUNITY-BASED TEAM?

The team approach allows individuals from a variety of backgrounds the opportunity to work together for the welfare of children and families within the community. This opportunity is very beneficial to child care providers, pre-school personnel, social workers, nutritionists and other providers. Providers who routinely work with children with special needs but may feel left out or disconnected.

The value of the community-based team should not be underestimated. Members of the team contribute information on what services are available, how services are organized and provided locally, what networks exist outside the community, current strengths and weaknesses, past successes and failures, and where gaps and duplication exist. The community-based team has a collective knowledge that can't be obtained from any other source. Based on this knowledge the community-based team can plan comprehensive and coordinated services that are appropriate for their community. The community-based team instills ownership. Continued commitment to the community-based team will increase the visibility and credibility of the team. The community-based team is the key to comprehensive coordinated care. Depending on needs and local resources, the community-based team may involve more than one community or even cover a designated area. One team may choose to be more structured and meet on a regular basis, while another team rarely meets face to face with most issues being resolved over the phone or through alternate channels.

LOCAL COMMUNITIES ARE BEST QUALIFIED TO PLAN, DESIGN, AND IMPLEMENT comprehensive coordinated services

STEPS TO ESTABLISHING A COMMUNITY-BASED TEAM

- **Personal commitment to teamwork**
- **Develop communication methods that address the needs of all team members**
- **Make a commitment to solve problems in a positive, timely fashion**

Teamwork is an ongoing process. Teamwork requires that individuals with different backgrounds, training and priorities make a commitment to work together toward common goals. Providing family-centered, community-based and coordinated care for children with special needs requires this type of commitment. You may not consider yourself an active member of the team but you promote teamwork whenever you provide care in a family-centered and coordinated fashion.

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THE COMMUNITY-BASED TEAM MIGHT INCLUDE

- community health care providers
- providers of community services or programs
- families of children with special needs
- civil, religious and child advocacy organizations
- local public officials and community leaders
- educators
- child care providers

The goal of the team never changes although the members of the team that work directly with the family will vary depending on the needs of each child and family.

COMMITMENT TO COMMUNITY TEAMWORK WILL

- improve communication and collaboration
- address the needs of everyone involved with the child
- improve services for the child and family
- establish a forum for problem solving
- expand the expertise and competence of all team members
- enhance efficiency for future cases

With experience and continued commitment the community-based team can work to find long term solutions to:

- the planning of services
- the delivery of services
- the funding of services

CASE MANAGEMENT/SERVICE COORDINATION

Developing a family-centered, community-based, coordinated system of services should not depend on case management services. One of the goals of family-centered care is to assist and support families so they can develop the necessary skills to manage their child's care. In a truly family-centered and coordinated system parents and providers work in partnership to plan, implement and coordinate the child's care. The community-based team organizes and coordinates services within the designated community, which in turn supports the child and family within the community.

Although most families don't require case management services families usually require assistance assessing their child's needs and obtaining services. Providers who assist families in this process can be compared to a type of broker or service coordinator. Depending on the needs of the family the team may want to designate one provider to act as a broker to a particular family.

In some instances team members may decide that case management services are necessary. The particular types of services required will vary depending on the complexity of the child's condition, the family's ability to cope, the family's support systems, additional family stressors, and limitations of the parents or family. These services may be determined necessary on a short or long term basis. The team should decide who can best provide case management services for a particular family and then support the case manager through information sharing. The ultimate goal of case management is to help families gain the skills necessary to assume this role.

Case Management Services
-ideally provided by the family
family=love and long term commitment=logical case manager

Broker or Service Coordinator
-helps the family identify needs
-responds to the needs of the family while recognizing the family's resources and abilities
-knowledge of community, programmatic, and financial resources
-understands ethnic and socioeconomic diversity
-communicates with parents and professionals

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PARENTS AND FAMILIES NEED SUPPORT

The dictionary defines support as, "to hold up," "to encourage," "to help." The discovery that your child has "special needs" presents a challenge and usually major life changes for the entire family.

Think of the challenges these families face:

- obtaining appropriate services
- paying for services
- adjusting to the illness or disability
- coping with new dynamics in the family
- finding their place in the community redefined

Typical Reactions to chronic illness or disability

shock
denial
sadness
anger
acceptance

The initial reaction to the news that a child has special needs is usually one of shock and possibly even denial. The grief that parents experience is ongoing and may be filled with mixed emotions. Transition points in the child's life (i.e. preschool to school, school to work, home to hospital, etc.) are especially difficult for the family. Periodic or ongoing anger is also a normal response to many of the challenges that families face. This anger may be misunderstood by providers and can serve as a barrier to developing an effective working relationship with the family. Providers must acknowledge parent's feelings, reassure parents that these feelings are normal, and refer parents to appropriate support services. Providers can help families realize the joys and rewards of raising a child with special needs.

Some parents express frustration because they feel that they are left out of the communication regarding their child's care. Some parents become passive because they fear their child will not be cared for or they feel intimidated by their lack of knowledge. Providers can offer support and empower parents by educating them about their child's condition, by sharing information, and by including them in the decision making process. Allowing parents to be actively involved serves the child's best interest.

The Medically Fragile or Multiply Disabled Child

Providers must be keenly aware of the needs of the family that is caring for the medically fragile or multiply disabled child. These children require constant care and supervision. A simple trip to the grocery store now requires planning. Think how physically, mentally, and emotionally draining this would be for any family. Enabling parents to care for their medically fragile or multiply disabled child at home requires community based support, planning and involvement.

Respite Care

Respite care gives families a break from the constant care required by a child with special needs. Respite care programs offer valuable support to families. Respite care programs are available in various communities throughout Wyoming and also through a statewide program administered by the Division of Developmental Disabilities, Department of Health.

Why Is Parent-to-Parent Support So Beneficial?

- reassurance comes from others who "have been there"
- parents serve as positive role models
- parents offer "inside" information on services, parenting techniques, and life style adjustments

Parent support groups originated when families facing similar issues reached out to others for understanding, support, and information. While mutual support and information sharing remain the core of their mission, parent groups have also increased their activities in the areas of child advocacy and public education. Parent groups empower parents to become effective advocates for their children. Health care providers need to recognize the value these services have for families, support these programs, and refer families to these programs.

Parent Support Groups Provide:

* one-to-one interaction
* emotional support
* assistance in learning to work effectively with professionals
* workshops
* educational meetings
* social groups or functions
* specialized support groups, peer groups and sibling support

The parent support groups across the state are helping families meet the challenges and share the joys of raising children with special needs. Support from other parents who have had similar experiences is reassuring and empowering. The needs of the family will change over time and parent support groups help families meet these changing needs.

Sibling Support

Having a child with special needs impacts upon the entire family. The family frequently finds their time, energy and resources focused on the child with special needs. Addressing the needs of other family members and maintaining balance within the family is very difficult. Siblings of a child with special needs express a range of emotions and responses similar to those felt by most brothers and sisters--although the love, empathy, pride, guilt, anger and support may be magnified. The need for sibling support should not be overlooked by parents and providers. One of the added benefits of parent to parent support is the support extended to the entire family. Children have the opportunity to network with other children who are dealing with similar problems and successes.

Parent Support Network

The parent support organizations across Wyoming have made remarkable strides in defining and coordinating all of their services. Their network includes (but is not limited to) ***Family Support Group Coordinators****, who are volunteers trained through the Governor's Planning Council on Developmental Disabilities;* ***Parent Coordinators*** *who are employed through the school or other service providing agency; and* ***Pilot Parents*** *who are employed through the Parent Information Center.*

Governor's Planning Council on Developmental Disabilities
1-800-438-5791 or 777-7230
Herschler Building, 4th Floor East
Cheyenne, Wyoming 82002

The Council provides planning, advocacy on behalf of persons with developmental disabilities, monitoring and evaluation of the service system. They have funds available to support projects which increase the integration, productivity and independence of persons with developmental disabilities. The Council provides training for Family Support Group Coordinators across the state.

The Council, in conjunction with the Wyoming Department of Health, Division of Developmental Disabilities, also publishes "Pathways to Information". Pathways is a directory of services for individuals of all ages with developmental disabilities. The directory lists the parent support contact persons for the state. Contact the Council if you are currently not receiving "Pathways to Information".

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Parent Information Center
1-800-660-WPIC (9742) or 684-2277
5 North Lobban
Buffalo, Wyoming 82834

PIC is a project of Parents Helping Parents of Wyoming, Inc. and is funded through the US Department of Education. The PIC office provides information to parents and professionals on specific disabilities and disability services available in Wyoming. Pilot parents are employed across the state to provide individual support and information, as well as to facilitate parent support groups. PIC publishes an informative bimonthly newsletter (free of charge) which you can obtain by writing or calling PIC.

Parent Coordinators/Parent Resource Centers
Local School Districts

Several local school districts in Wyoming have used a portion of their Title VI-B funds to provide Parent Coordinators and Parent Resource Centers in their districts (these include Casper/Cheyenne/Evanston/Lovell/Powell/Rock Springs/Weston County/Worland). The Centers have available for checkout books, videos, audio tapes, and other information on disabilities. The Parent Coordinators are parents of children with disabilities who are hired to provide support to other parents and work as a liaison between parents and the school district. Contact your local school district for more information.

Protection & Advocacy System, INC.
2424 Pioneer Avenue, Suite 101
Cheyenne, Wyoming 82001
TTY or Voice 632-3496 or 1-800-624-7648

Protection and Advocacy (P&A) is a private, non-profit corporation that performs its duties independently from any agency, whether it be public or private. P&A is the official agency authorized by the Governor to implement certain mandates of several federal laws, these laws provide various advocacy services. P&A has the authority to investigate complaints made by any person with developmental disabilities, his or her legal guardian, or next friend.

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Transition and Related Issues

We all want to see our children grow to their full potential. To grow to be responsible, self-confident and productive adults who have a sense of belonging to a family and a community. When a child is born with special health care needs the hopes and dreams are still the same--they just may need to be modified.

Providers must be very sensitive to the fact that families have hopes and dreams even when their child has a fatal or progressive condition. They hope their child knows he is loved; they hope their child doesn't suffer; they hope providers really care about their child; they hope for the best for their child.

We have the opportunity to design a comprehensive and coordinated system of services that addresses the changing and complex needs of children with special health care needs. We can improve outcomes of care and help more children reach their full potential.

Growing Concerns Over Transition

10 to 15% of all children born in the United States are born with a chronic or disabling condition. Of those, nearly one third have disabilities which limit activities of daily living. Over the past 20 years improvements in neonatal life support technologies and medical/surgical interventions have lead to a decrease in early childhood mortality. Over 85% of children born with chronic conditions and disabilities will survive to adulthood. The challenge for the future is not the development of additional technologies, instead it is learning to provide the social and developmental support that these youth and their families require.

What Is Transition?

As the child grows and needs change, so must the services we provide. This process of change and providing services that support change is commonly known as transition.

It might be helpful to think of transition as the road that the child and family must travel to reach their destination. The destination is different for every family. The family may have to change their plans or choose a new destination after starting out. Once on the road the family may find that the road is filled with curves and detours; their car breaks down frequently; they wander off of the road and get lost; or the road has few signs or markings to indicate where they are or how much further they still have to travel. Hopefully the family will encounter people and services along the road that will help them on their way.

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How Do We Promote Transition?

All too frequently children with special needs fail to make successful transitions to adulthood. This is the result of looking at transition as a separate or isolated activity that is provided only by certain providers at prescribed times. Transition is routinely associated with the activities that begin in high school or just prior to the individual turning 21 years of age.

If we want to see more children with special needs make successful transitions to adulthood we must start looking at transition from a new perspective. Transition is a continual and collective process--each of us contributes to or detracts from this process. Any provider can support transition (beginning with the recognition that a child has special needs) by consistently providing services in a family-centered and coordinated manner. Family-centered and coordinated care supports the continued growth and development of the child and family, fosters self-reliance and builds self-esteem. These are essential components of successful transition. When we give the child and family the opportunity to develop these skills we ultimately support transition.

Supporting transition includes preparing families for change. Change is certain because the needs of the child and family will change over time. This includes a change from:

- **hospital to home and home to hospital**
- **specialty care to primary care/primary care to specialty care**
- **home to preschool, to elementary school, to junior high, to high school**
- **school to employment**
- **home to independent or supervised living**
- **child-centered programs to adult oriented services**

By providing assessment, planning and support we help families adapt to change. When families are not supported during times of change, then change can be a threat or a setback to the family. When a change in provider, teacher, program, or placement occurs the family often feels as if they are starting all over again. They must reestablish trust. As a provider you can easily alleviate the family's fears by letting the family know you value their input and respect their knowledge and experience. You do this when you let parents tell you about their child--his strengths, his fears, how he responds to certain procedures or treatments, what techniques are familiar, how certain behaviors or situations are handled at home, etc. These simple things are the basis for building trust. The family must trust you if they are going to have faith in your judgement, comply with treatment and follow through with recommendations. Taking the time to establish trust and respect will pay off in the long run.

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Optimal Development

The family is central to the lives of all children. It is the primary structure within which development occurs. Over time other individuals and experiences exert a greater influence on the growing child. This includes friends, peers, teachers, associations made through sports, clubs, church, social and recreational activities, etc. The gradual blending of these experiences help shape the child's personality as he grows to adulthood. The child with special health care needs or a disability is also greatly influenced by relationships with physicians, specialists, nurses, therapists, special education teachers, etc. Children with special health care needs require the same types of associations and experiences that any child requires to foster normal growth and development.

Concerns Associated with Puberty/Adolescence

The physiologic changes that occur with the onset of puberty are a source of concern for all young people. Even the healthiest young person feels different from peers and that no one understands how they feel. Chronic conditions can affect the onset of puberty. The young adolescent who does not enter puberty with his peers has persistent questions of adequacy.

The adolescent with special health care needs also has an increased sense of being different from his peers. Physical and health restrictions and medical care requirements can restrict a teenager's efforts to live life typically. In addition, the adolescent with a disability or chronic illness is usually more isolated than his peers. The combination of these things can lead to feelings of self-rejection and depression.

Independence, peer relationships, physical growth, and sexual maturation are major concerns for all young people. Adolescence can also be a time for experimentation and engaging in risk taking behaviors. These issues and concerns are the same for all adolescents, in fact many of these feelings are intensified for teens with special health care needs and disabilities.

Puberty appears to be one of three major transitions in the life of a young person with disabilities. The other two critical moments are the time of diagnosis and the time of transition from school and home to (ideally) work and independent living.

Promoting Adolescent Independence and Self-Determination

Adolescence is typically a time of self-exploration, expanding personal independence, dreaming about future options for work, college, and living, redefining relationships with parents, and developing additional support networks with peers and community members. All of these activities are essential if youth are to prepare for their quickly emerging adult roles, responsibilities, and privileges. Gradual expansion of independence is a normal and self-perpetuating process for most adolescents, but for the child with special health care needs or a disability this process is often not so spontaneous.

The developmental challenge of the teenage years involves learning:

- to take responsibility for one's own behavior
- to make choices weighing both personal needs as well as the needs of others
- to develop supportive relationships characterized by common interests

The challenge is the same for the teenager with special health care needs or a disability. Some of the factors associated with helping a child develop the skills necessary to achieve independence and optimal functioning are:

- family and peer support
- acknowledgement of one's physical condition while not viewing physical limitations as handicaps
- involvement with household chores (assigning chores is a measure of value and expectation by parents)
- having a network of friends with and without disabilities
- parental support without being overprotective

Family Issues

For many families who have teens with disabling conditions, puberty may represent a time of emotional crisis. Visually, parents are confronted with the reality that their son or daughter will not remain a child forever. Emotionally, families are confronted with the possible future limitations of the emerging adult. At this time parents and teens have a complex range of questions which need to be addressed:

- **Genetic Risk:** Some parents may have received genetic counseling when their child was young, with most questions focusing on the parents. Now there are a range of questions and concerns that need to be addressed which pertain directly to the young adult.
- **Life Expectancy:** With improved survival rates many young adults with previously fatal diseases of childhood are pioneers on an unchartered course. This can be a lonely and scary time for the entire family. Although little information may be available to the family, providers need to acknowledge these concerns and continue to support the family.

- **Sexual Capabilities:** Few young adults have been carefully assessed for sexual functioning and reproductive capability. Fewer still have received accurate information about their reproductive potential or the sexual options available to them given their physical limitations. Sexual needs and desires need to be addressed and not denied or ignored.

- **Social Skills:** The isolation often experienced by teens with disabilities or chronic health problems may result in a failure to develop the social skills critical to successful adult functioning. It is important to provide opportunities for teens to develop and enhance these skills.

- **Academic and Vocational Potential:** This is an area of critical concern with the vast majority of adults with disabilities unemployed and underemployed. Assuring optimal transition to adulthood requires assessment, planning and support that should begin in childhood.

Much like teens with disabilities, the families also tend to be more socially isolated than other families. The family may have less contact with friends and use community services less frequently than peers. The demands of the chronic or disabling condition during childhood and early adolescence may have been such that it was necessary for one parent (usually the mother) to limit out of home employment or other activities. As the teenager moves into young adulthood parents often must learn to shift the focus of their attention from child care to other activities such as employment, volunteer work or advocacy. This shift may not only benefit the parent it may also be associated with improved adolescent functioning. Young people with disabilities frequently indicate that their parents are overprotective. Although well intentioned, being over protective can convey a message of incompetence to the youth.

HEALTH CONCERNS FOR TRANSITION TO ADULTHOOD

Curriculum Development
Linkages With Agencies Outside School
Health Care After Graduation
Addressing Health Needs on the Job
Safety Issues
Mental Health
Sexuality
Medication and Appliances
Health Insurance

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THE PARENTS ROLE IN FAMILY-CENTERED CARE

Parents must assume a very active role in a family-centered system of care. Parents need to develop the skills to work as partners with a variety of providers. This isn't easy and parents can't do it alone.

How do parents develop the skills and confidence to work as partners with professionals? It requires hard work, information, communication, time, and lots of support and reassurance. Professionals must provide support and information so that parents can begin to develop these skills. Parents have to work at developing these skills. It is a two way street that requires new responsibilities for both parents and providers.

Parents are valuable members of the team that plans and provides services for the child. Parents bring a level of knowledge and expertise to the relationship that no one else possesses. Parents know their child and the needs of the family better than anyone.

What Can Parents Do To Promote Family-Centered Care?

1. Ask questions and expect answers.
2. Learn and read as much as you can about your child's condition, disease, disability.
3. Keep appointments, follow through with recommendations, etc.
4. Understand your child's condition, medications, treatments, etc.
5. Learn to discuss your child's condition in terms that can be easily understood by others.
6. Share pertinent information about your child with teachers, nurses, early interventionists, physicians, therapists, etc.
7. Help others understand the needs of your child and your family.
8. Learn to discuss your child's strengths and limitations, discuss what is needed for your child to succeed, work with providers to set realistic goals for your child.
9. Work with medical providers to develop a written health care plan for your child
   - clarifies information
   - defines responsibilities
   - states common goals
   - can be used by parents to communicate clearly with educators, other service providers, etc
10. Acknowledge your own limitations and ask for help when you need it
11. Contact the parent support group coordinator in your area (they provide support, information, networking opportunities, and advocacy)
12. Keep an up to date notebook or folder of all pertinent information (medical and educational).

Good Record Keeping Is Important

Good record keeping is an important part of parenting a child with a disability. It helps with educational and medical issues.

Records need to be kept up to date and should document your requests for services, the services provided, evaluations and any other information concerning your child's special needs. Your records are invaluable when planning services for your child.

Keep a notebook listing names, addresses and telephone numbers of the people who deal with your child. These include physicians, therapists, teachers, related school personnel, other service providers, insurance providers, Social Security or SSI contracts, etc.

Red flag any allergies or medical conditions your child has in a prominent place in the notebook. List the name, address and phone number of anyone designated to sign for medical attention should you not be available.

List all medications your child takes at home and at school. Note the name of the medication, prescription number, and time/dosage information.

Include a section in the notebook for writing down your questions and the answers you receive from education, medical or other providers--date your notations. Include notes about telephone conversations and notes from parent/teacher conferences.

File copies of all school reports, IEP's, psychological reports, etc. in the notebook. Include copies of test results and recommendations from assessments you have had done independently of the school.

Writing down every contact you have with professionals can seem like a hassle at times, but it can make a huge difference if you need to go back and find information or back up something you say.

Getting Off to a Good Start With the School: Planning for Your Child with a Chronic Health Condition

- Schedule a planning meeting with the school nurse, don't just drop in. The school nurse can help you obtain appropriate services and ensure that school staff receive the information they need to understand how your child's condition might affect learning or behavior.

- Write a letter to the school principal to request a meeting to discuss the details of your child's health management at school. The school administrator is responsible for ensuring that all of your child's health and educational needs are identified and services are provided. Developing a formal written plan with the school may be your best way to organize information about your child's needs and to document decisions about school services.

- Ask about teachers who may be more experienced or more comfortable than others having a child with special health considerations in the classroom.

- Help your child develop self-care and communication skills. Your child needs to become knowledgeable about his or her condition, it is also helpful if your child can explain health management routines to others.

- Ask your physician about medication formulations or dosage schedules that may reduce the number of doses required to be taken at school. When medications must be taken at school work with school personnel to ensure that medications are properly administered.

- Provide educational materials and resources to school personnel regarding your child's condition or treatment. Work with school staff on the proper operation and maintenance of your child's equipment. Your doctor, nurse, therapist or equipment vendor may even be willing to come to the school and work with school personnel.

- Obtain school authorization forms for medication and emergency treatment so your doctor can fill them out during a routine office visit. Keep a supply of forms on hand to avoid delay and inconvenience when changes are necessary.

- Provide the school with your emergency numbers promptly so that your child's record's are complete on the first day of school. Keep names and numbers up-to-date. Make sure your back-up people know about your child's needs and are prepared to act in your place when you can't be reached in an emergency. Also provide current authorization for emergency medical treatment, the physician's phone number, and any other pertinent information.

- Talk with your child's previous teachers or day care providers to see how your child's condition may affect school performance. It may be helpful to review your child's school file.

IEP MEETING PREPARATION CHECKLIST FOR PARENTS

1. Obtain and study all school records, including private assessment, medical records, etc.

   _____ Prior IEP's

   _____ Progress notes, report cards, teacher' notes, etc.

2. Make a list of your child's present level of functioning based on your observations.
   _____ Academic skills

   _____ Developmental skills (if Pre-academic)

   _____ Motor skills

   _____ Language skills

   _____ Emotional/behavior skills

   _____ Self-help skills

   _____ Pre-vocational & vocational skills

   _____ Others

3. Make a list of goals you feel your child should have.

4. List related services you feel your child may need.

5. List special education services you feel your child may need.

6. If you wish to record the meeting, be sure to bring a tape recorder.

7. You may bring along an interested person to provide support.

HEALTH AND MEDICAL SERVICES

The Importance of Family-Centered Medical Care

Health care providers are key players in a system of services for children with special health care needs. Children with special health care needs are usually identified at birth or during early childhood through contact with the health care system. Many of these children will require substantial medical intervention. **Medical providers usually provide families with their first glimpse of the system.** The family may be required to work with a variety of providers over the years as the child grows--first impressions are very important.

All health care providers must provide family-centered care!

This is the first, and may be the most important step, in improving services and outcomes for children with special health care needs. This applies whether you are a primary care provider in the local community or a subspecialist at a tertiary care center. All providers must recognize the family as the constant in the child's life and the essential component to the outcome of care. You do this by acknowledging the family, providing complete information, encouraging questions, and involving the family in the decision making process. When medical professionals consistently treat families in this manner families learn to trust and have confidence in medical providers. This is essential for the family's continued growth and ability to plan and provide care for their child. All providers must be responsible for fostering the family's ability to care for their child, regardless of the level or duration of involvement. The way professionals treat families is the key.

The Importance of Coordinated Medical Care

All health care providers must learn to work together to provide coordinated medical care. Organizing medical services for children with special health care needs requires coordination of services between primary, specialty and tertiary care.

- Level I (primary care)
- Level II (specialty care)
- Level III (tertiary care)
  refers to highly specialized care that may be required for children with complex, chronic or life threatening conditions. These services are usually provided in high technology diagnostic treatment centers. Wyoming has no Level III centers. Wyoming maintains cooperative working agreements with Level III providers in surrounding states.

"Wyoming's shortage of primary and specialty care physicians and lack of instate tertiary care emphasizes the need to provide coordinated care."

The child's need for medical services will vary over time. At times the child may need only regular health supervision and acute illness care as required by all children, and at other times the child may need highly specialized treatment and services. Developing a community-based system of services for children with special health care needs requires that medical services be coordinated between all three levels of care. Medical providers at all levels facilitate this process through communication and networking with other providers. Families frequently must travel significant distances to obtain even primary care. Primary care providers provide first contact care. They are instrumental in preventing gaps and duplication of services by knowing how specialty care is organized in their area and within the state. This allows for maximum use of existing services within the state and efficient out of state referral through appropriate channels.

Medical Services Need to Promote the Child's Growth & Development

Children with special health care needs or disabilities normally require long term medical intervention, although the level of care required may vary greatly. In addition to providing care and services that meet the child's medical needs, providers must not overlook the developmental concerns and challenges of the growing child. Children with special health care needs do grow up. Frequently parents and providers fall into such a routine of planning, managing and providing a child's care that they forget to ever include the child. Many questions and concerns, suddenly, become an overwhelming issue when the child reaches high school and everyone realizes that this child will soon be an adult. Providers and parents must not forget to include the child in his/her care whenever possible and as soon as possible. Help the child learn to make successful adaptations and to manage his/her care (to the greatest extent possible). By helping the child acquire a sense of control over his/her medical management we empower the child and help the child view his health care as less rigid and more flexible.

Providers and parents encourage the child to participate in the health care system if they:

1. **Talk to the child about his condition, disease, disability (use age appropriate language and comparisons).**
2. **Encourage the child to ask questions or ask the child questions.**
3. **Allow the child to take some responsibility for providing his own care, whenever possible.**
4. **Let the child participate in making decisions about his care, whenever appropriate.**
5. **Talk with the child about developmental changes and specific concerns.**
6. **Teach the child how to manage and control his\her condition (the child may have to learn to live with a daily health concern or disability--one that lasts a lifetime).**
7. **Provide health guidance to promote health and prevent disease.**
8. **Provide services in an age appropriate setting and fashion.**
9. **Involve the child in planning services whenever possible (this is very helpful when a child makes the transition to a new program or service).**

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THE MEDICAL HOME

The medical home is a key component in a family-centered, community-based, coordinated system of services for children with special health care needs. The medical home refers to primary health care that is comprehensive and addresses the needs of the whole child. This includes continuity of care, timely detection and management of early childhood problems, as well as coordination, referral and follow-up. Ideally, the child's primary care physician provides the medical home. The medical home provider needs to be kept informed when the child is receiving any primary care services outside of the medical home. This will help assure that these services are being provided in a coordinated and cooperative manner.

The medical home provider works closely with the family to help plan and coordinate medical services at all levels. A strong medical home reassures the family that a competent professional is taking into account all aspects of their child's medical and health care. The family knows their child is receiving the routine care required by any child; their child is being referred appropriately for specialty care; and that medical recommendations will be interpreted and implemented appropriately with consultation and follow-up as needed.

The American Academy of Pediatrics states that the comprehensive health care of infants, children and adolescents (the medical home) should encompass the following services:

1. Provision of preventive care including, but not restricted to, immunizations, growth and development assessments, appropriate screening, health care supervision, and patient and parental counseling about health and psychosocial issues.
2. Assurance of ambulatory and inpatient care for acute illnesses, 24 hours a day, 7 days a week; during the working day, after hours, on weekends, 52 weeks of the year.
3. Provision of care over an extended period of time to enhance continuity.
4. Identification of the need for specialty consultation and referrals and knowing from whom and where these services can be obtained. Provision of medical information about the patient to the consultant. Evaluation of the consultant's recommendations, implementation of recommendations that are indicated and appropriate, and interpretation of these to the family.
5. Interaction with school and community agencies to be certain that special health needs of the individual child are addressed.
6. Maintenance of a central record and data base containing all pertinent medical information about the child, including information about hospitalizations. This record should be accessible, but confidentiality must be assured.

Providing the medical home for children with special health care needs is a rewarding yet challenging experience. It is important to be aware of personal needs and limitations. If you do not feel comfortable providing the medical home for a particular child, express this to the family and refer the child to a physician who you feel can provide this care.

The medical home provider looks at the comprehensive needs of the child and family and links the family to other appropriate services. These include:

- **early intervention services**
- **social work services**
- **educational services**
- **family support services**
- **vocational services**
- **mental health services**
- **financial or medical assistance**
- **respite programs**
- **nutrition services**
- **public health nursing**
- **community programs**

MAKING EFFECTIVE REFERRALS

Know what services are available in your community and how to access those services. A phone call to find out more information about local programs or agencies is well worth the time. It is helpful to establish a contact person with key providers and agencies. You may want to develop a simple interoffice referral checklist that lists local and area providers. The checklist can be placed on the patient's chart and serve as a quick reference for the entire staff to determine what referrals were made and when. It is also a useful tool to provide proper follow-up.

The referral process can be greatly facilitated by effective networking within your community. Although this is traditionally where the system breaks down it is an opportunity to create an effective team to support the child and family.

WHY PROVIDE A MEDICAL HOME?

It benefits the child. *Children who receive consistent comprehensive health care have better general outcomes. Of all the professionals involved in services for children, you usually see the child first. You may be the only professional a child sees until he/she reaches school age.*

In parent's eyes you are both an accessible expert and a child advocate. Your office may feel like the natural entry point for needed services and information on their children. You are the first line of defense in preventive health care.

It benefits your practice. *The medical home will enhance time management and is cost effective. Continuity of care facilitates effective parent-professional relationships. Time spent on anticipatory guidance will result in fewer emergencies and more efficient office visits. Early diagnosis and mediation of problems often reduces cost and complications when the child is older.*

Providing a medical home can make your practice more enjoyable. It allows you to experience the art of medicine as well as the science.

The medical home assures patient satisfaction. Parents develop a sense of loyalty when they feel you are concerned about their child.

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The Physician and PL 99-457

Public Law 99-457 provides early intervention services for young children who are disabled or developmentally delayed from birth to age five. Early intervention services provide primary care physicians with a valuable resource for their patients who have disabilities or who are at risk for developing delays. In Wyoming, the Division of Developmental Disabilities funds these services for children, through contractual agreements with developmental centers located around the state.

The physician has an active role in the provision of these services:

1.Referral of infants at risk.
The physician must be knowledgeable of factors that place an infant at risk for developmental delays, including biologic or environmental factors. The Wyoming Department of Health has initiated the statewide "Healthy Start" tracking program as a means of identifying (as early as possible) and tracking children "at risk" for developmental delay.

2.Early identification and case finding.
The physician must be able to identify infants who are not recognized at birth, but who later demonstrate developmental delays. Office practices that are alert to developmental concerns, even if the child is seen only for sick care, are desirable.

3.Medical diagnosis.
The physician provides a thorough medical examination to determine if there is a specific medical diagnosis and associated findings. Referral to specialty care may be considered necessary for diagnosis or evaluation (i.e. nutritional assessment, genetics, developmental pediatrics, neurologic evaluation, etc).

4.Ongoing communication.
The physician's input should not end with referral to early intervention services. The physician's knowledge of the child, the family, and the medical diagnosis provides vital information and recommendations for developing a plan of services for each child and family (Individual Family Service Plan). Once the plan has been implemented the physician continues to provide on-going medical care and input as appropriate.

5.Advocacy.
Physicians can serve as effective advocates for children with special needs and their families.

Early Intervention Programs: Where do physicians fit in?

An effective early intervention program provides developmentally appropriate experiences that are tailored to the individual needs of the child and family. The program should offer family support and parental involvement. Ideally parents will learn strategies that will foster their child's total development.

Physicians can work with and assist early intervention programs in the following ways:

1. **Learn about the early intervention program in your community.** Talk with the staff of the early intervention center, visit the center, develop a relationship that provides a source of continuing education for all parties.

2. **Determine the need for referral to an early intervention program.** Ask yourself "What do this child and family really need and what can the early intervention program provide." This requires knowledge of intervention strategies in order to prescribe more comprehensive and specific services.

3. **Provide a diagnosis as soon as possible.** Prolonged use of the term ***developmentally delayed*** may provide false hope and does not give anyone an idea as to the child's prognosis. For the infant with atypical or slow development you may not be able to make a clear diagnosis or prognosis. In this case you will need to work with the parents and staff of the early intervention center to develop a rational service plan.

4. **Talk with parents as soon as possible about the significance of their child's disability and its long term implications.** Work with the parents and early intervention center to set realistic goals from the start. Inaccurate pessimism can be as damaging as unrealistic optimism.

5. **Educate early intervention staff about the natural history of neurologic and developmental disorders.** This avoids promoting false hope for parents when little improvement or progressive deterioration can be expected.

6. **Make appropriate referrals** for more specific diagnostic and therapeutic recommendations when needed.

7. **Request periodic reports** from the early intervention program on the child's and family's progress.

The Physician's Role in Special Education

Prior to the 1970's physicians were often asked to exclude children from school by certifying that the child's physical or medical condition prevented the child from attending school. Now physicians are being called upon to participate in the evaluation of children and determine the need for special services at school.

Physicians must work to ensure that a child's medical needs are not being overlooked when planning educational services. When sufficient medical information is not provided parents and educators must interpret a child's health and medical status without knowing the physician's assessment or recommendations. Educational goals should fit with medical and physical findings. The physician's input is very helpful in writing the child's school health care plan.

As a Physician You Can:

1. Provide a diagnosis whenever possible.

2. Discuss the results of your evaluation with the parents, include the school if appropriate
   -reinforce information and recommendations in writing (facilitates clear communication).

3. Explain what is and is not understood about the child's condition, treatment and prognosis.

4. Provide information on the child's history and current neurologic, nutritional and developmental status.

5. Participate in development of the child's IEP or school health care plan
   -communicate in writing, attend a meeting at school, work directly with the school nurse and the child's parents.

6. Develop a written health care plan with the parents
   -clarifies information
   -delineates responsibility
   -common goals are stated
   -can be used by parents to communicate clearly with the school or developmental center

7. Physicians are advocates for children. Acquaint parents with their rights and coach them in ways to approach school systems.

SPECIAL NEEDS CHILDREN--THE NURSE'S ROLE

Nurses work in a variety of settings providing generalized and specialized nursing services for children and families. This includes prenatal clinics, newborn nurseries, neonatal intensive care units, pediatric units, physicians' offices, public health, mental health, home health, early intervention centers, and schools. Nurses are valuable members of the multidisciplinary team. Registered nurses have training and experience in health promotion, disease prevention, health care management, developmental and family issues, community and home based services, and multi-disciplinary team participation.

Nursing interventions routinely involve interpersonal interactions with the child and family. As a result families frequently bond with nurses. The family may voice their concerns, direct questions, request information and seek reassurance from a nurse. It is not unusual for a nurse to become the intermediary between the family and other providers. Nurses are in an ideal position to acknowledge parental concerns, open lines of communication, and initiate the referral process. They are effective advocates for children with special needs, and they can help parents become effective advocates for their children.

Working in a variety of settings, nurses play an important role in the development and delivery of comprehensive services for children with special needs. Nurses are frequently the gatekeepers.

As members of the community based team nurses provide the following services:

1. Prevention of health and developmental problems for infants/children/families
2. Early identification or casefinding
   -this may include assessment and evaluation activities depending on the nurse's training and scope of practice
   -seek complete assessment of the child via referrals and follow-up
   -the nurse's understanding of family dynamics, and knowledge of risk factors can lead to early identification and intervention
3. Comprehensive assessment of the family's total pattern of health
   -health management, nutrition, elimination, sleep, exercise, stress, family and community supports, knowledge, etc.
4. Timely and appropriate referrals based on knowledge of available services and access to those services
5. Care coordination
   -may be desirable depending on the needs or limitations of the family or the complexity of the child's condition
   -effective care coordination requires that team members support this activity and share information with the care coordinator
6. Participate in planning services to meet a child's developmental, educational and vocational needs
7. Administration of medications and treatments prescribed by the physician
8. Provide information and instruction to the family
   -provide information to help families understand their child's condition and training to help families meet their child's special needs

9. Serve as a liaison between the family and other providers
   -most families need support and guidance when they first find out their child has special needs
   -a positive experience can help the family grow and move forward
10. Help families develop the skills to become active participants in planning services to meet their child's special needs

THE ROLE OF THE SCHOOL NURSE

School nurses are ideal advocates for children with special needs. They are in a unique and pivotal position because they provide a direct link between the medical and educational community. School nurses are valuable members of the community-based team.

School nurses are keenly aware of factors that place children at risk for delays, child abuse, drug and alcohol use, poor school performance, dropping out, etc. They have the opportunity to advocate for children with special needs even if the child doesn't qualify for special education services.

Every school in Wyoming does not have a school nurse but every school district employs a nurse. Although the nurse may not be able to provide direct care for every child the nurse consults and collaborates with local schools and serves as a resource.

The Wyoming Department of Education, Rules and Regulations for Serving Children With Disabilities states the following definition. "School Health Services" means services provided by a certified school nurse or other qualified person; services may include:

a.) health related assessment/evaluation
b.) planning and provision of health related care; and or
c.) liaison work with community agencies and community health care providers

The school nurse participates in the following activities:

1. Identify children in need of special programs or services
   a.) participate in Child Find activities
   b.) collaborate with the Developmental Center or Headstart Program in your area
      - promote transition of these children at school age
      - work with the educational staff to meet the needs of these children (routinely they don't qualify for special education services)
   c.) direct all in-school health screening programs to identify health concerns, including vision and hearing
   d.) follow up on all health screening failure by contact with parents, refer for appropriate professional services, and monitor health needs in school
   e.) refer students for evaluation for special education services when health concerns have educational significance

2. Conducts health assessments through classroom observation, parent interview, home assessment, etc.
    a.) obtain a health and developmental history
    b.) evaluate the child's current health status
    c.) request information from the physician or other primary care providers
    d.) identify health problems requiring interventions
        -training of school personnel, safety measures, pain relief, self care assistance, transportation, medications at school, special diet, eating assistance, etc
    e.) summarize health information in educator terms
3. Work to assure that the medical needs of children with special health care needs are not being overlooked in the school setting
    a.) make sure all pertinent medical information is available to appropriate school personnel (follow-up when this information is not available)
    b.) arrange for a medical examination by a licensed physician when indicated
    c.) develop networks with local health care providers
    d.) communicate with the child's Medical Home provider
    e.) function as a liaison between the educational and medical communities (promote the concept of a team approach)
4. Develop an individual health maintenance plan with the student or parent if indicated
5. Provide direct health care services appropriate to meet the child's special needs while at school
    a.) may include the administration of medications and special treatments prescribed by a physician (with parental permission)
    b.) consult with the physician as needed
    c.) supervise those activities when provided by other school personnel
6. Participate as an active member of the Multidisciplinary and IEP Teams
    a.) ensures incorporation of the health component in planning services for the child
        -the child may not qualify for special education but still be in need of special services or interventions
    b.) as a member of the Multidisciplinary and IEP Teams the nurse
        - assures that pertinent medical information is available
        - summarizes health information in educator terms
        - helps identify the health needs of the child
        - helps determine what services are required to help meet the child's medical needs
        - participates in development and review of the child's IEP or School Health Care Plan
7. Provide support and training to school personnel working with children who have special needs, or provide access to other professionals who can provide the training
8. Develop an ongoing relationship with the family
    a.) supports and reassures the family
    b.) provides a consistent point of contact when families need to discuss concerns, exchange ideas, vent frustrations, etc
9. Help the family identify and access appropriate community resources in a timely manner
10. Become an effective advocate for children and their families

The School Nurse and Children With Chronic Health Problems

The school nurse assists students, parents, and teachers to adapt to students' chronic health problems. These chronic health problems may include diabetes, epilepsy, allergy, asthma, attention-deficit disorder, nephritis, cancer, amputee, etc. Most of these children can function in a general school program, if school personnel are aware of the child's health problems and special needs.

The following is recommended:

1. Any student with a known or suspected disability or chronic illness should be referred to the school nurse.
2. The school nurse:
   a.) discusses needs and concerns with the parents and the student
      - together you devise a plan to meet the child's school health needs
      - involving parents demonstrates that you value their knowledge and experience
      - encourage this interchange on a continuing basis

   b.) explains the child's medical condition and special needs to teachers and other pertinent staff
      -interprets medical information
      -provides inserivce and training as indicated (i.e. proper operation of special equipment, side effects or reactions to prescribed medications, what to do in a medical emergency, special meals and supplements required to meet the child's nutritional needs, etc)

   c.) provides direct health care services appropriate to meet the child's special needs at school
      -includes the administration of medications, special diets, supplements, and special treatments prescribed by a physician (with parental permission)
      -consults with the physician as needed (with parental permission)
      -supervises medical activities when provided by other school personnel

   d.) records information in the student's health record

   e.) assists in coordinating services between the health care provider, the school and the family

THE ROLE OF THE PUBLIC HEALTH NURSE
Related to Special Needs Children

Public health nurses are ideal advocates for children with special needs. The entire family may utilize services provided at the local public health facility. This includes immunizations, well child check-ups, WIC, family planning, Best Beginnings, communicable disease control, etc. Public health nurses are also the local representatives for Children's Health Services. As a result public health nurses routinely maintain long term relationships with families.

Home visiting is another important aspect of public health nursing. Public health nurses have the opportunity to work with the family on the family's "turf," providing health guidance and services that are tailored to address the family's needs within their home. Public health nurses are important members of the community based team.

The public health nurse participates in the following activities:

1. Early identification of children with special health care needs
   - -agency programs, policies and training opportunities support early identification
   - -participate on interagency/multidisciplinary teams
   - -network with developmental centers, schools, Headstart, day care centers, physicians, etc.
2. Timely and appropriate referrals
   - -network with area providers to facilitate this process
   - -become directly involved in the referral process if indicated by family needs or limitations
   - -follow-up on referrals (routinely this is where families fall through the cracks)
3. Comprehensive family assessment
   - -in the family's home
   - -assess family strengths and limitations, coping, knowledge of diagnosis, knowledge of medical plan, support systems, financial needs, etc.
   - -assess the family's pattern of seeking primary and preventive health services (encourage the family to establish a medical home)
4. Application to Children's Health Services (CHS)
   - -PHN's are local representatives for the program
   - -assessment of the child's current status, functional limitations, nutritional needs (which may require referral to a local Registered Dietitian), immunizations, barriers to care, active resources, etc.
5. Provision of care coordination or service coordination
   - -when indicated by the family's needs
   - -available to children on CHS
   - -ultimately you will help the family assume this role
6. Facilitate communication between the family, the Medical Home and other providers
   - -help families develop effective communication skills (fosters self-reliance)
   - -help the family identify their role in family-centered care

7. Provide support and reassurance to the family
   -maintain an ongoing relationship with the family
   -provide the family a consistent point of contact
   -very beneficial during times of transition between providers and programs
   -link the family to area support groups and organizations
8. Provide information and training to the family
   -assess the family's knowledge of the child's condition, special needs, medical plan, etc.
   -very important when the child comes home from the hospital
   -tailored to meet the family's needs within the home setting
   -provide health guidance emphasizing health promotion and disease prevention
   -foster the child's and family's ability to manage and control the child's chronic condition
9. Administration of medications and treatments under the supervision of a physician
   -may be provided in the home depending on the child's or family's needs
   -observe for adverse reactions, side effects, proper administration, etc.
   -consult with and provide feedback to the physician
   -training and oversight when other caregivers provide these services
10. Planning services to help meet the child's developmental, educational and vocational needs
   -actively participate on the interdisciplinary team
   -participate in development of the IFSP, IEP, or school health care plan

EARLY AND PERIODIC SCREENING

As a primary care provider, one of the most important services you provide children and families is early detection of problems and linkage to needed services. You may be the only professional to see a child prior to admission to school. Early and periodic screening is essential to early detection and intervention. Early detection and intervention may prevent the occurrence of more severe problems. Many chronic conditions such as vision and hearing problems are characterized by "silent periods" that precede the point when symptoms become apparent. Three types of children can be identified early for prevention and early intervention.

1. Developmental delay refers to delays in one of the six major areas of development.

language	gross motor	fine motor
cognitive	self-help	social

The best single predictor of developmental delay is delayed language development. The most frequent complaint of parents of children with developmental delay are language concerns. Parents may be one of your best assets in screening for developmental delays.

2. Biological risk is usually the most easily identified. These children have a physical or mental condition which has a high probability of resulting in limited functioning. Examples include:

prematurity	failure to thrive	sensory impairment
Down Syndrome	fetal alcohol syndrome	asphyxia

3. Environmental risk can be identified by considering the presence of a variety of risk factors. These might include:

teen parents	substance abuse	disturbed bonding
hx of child abuse/neglect	parental disability	economically disadvantaged

Currently the fastest growing group of children needing the greatest amount of consideration from health care providers and educators are children with serious emotional disorders. Many of these children have associated learning disabilities or behavior problems that place these children at enormous risk.

How Do You Assure Early Identification of Developmental Irregularities?

Does formal screening fit into your busy office practice? Providing regular periodic screening for all of the children you see may seem overwhelming initially. There are ways of beating time constraints. It will require commitment and creativity from you and your staff to see that regular developmental screening is accomplished. Utilizing the waiting room to have parents complete developmental questionnaires may be helpful.

Crucial Components of Effective Screening:

1. An awareness of the family's medical history
2. Physical examination
3. Parent's observations of the child
4. Utilization of formal screening tools

Important Aspects of Developmental Screening:

1. Recognition that it is important
2. Screening process is "user friendly"
3. It is done on a regular basis
4. Time saving mechanisms are put in place

The Importance of Anthropometric Measurements

Infants and children grow at a rapid rate. Growth is an important indicator of health, nutritional intake and physical development. Anthropometric measurements can lead to the identification of chronic disease, infection, maternal deprivation, adequate or inadequate caloric intake, metabolic disorders, feeding problems, etc.

Lengths\heights and weights are a valuable screening and assessment tool because they can be easily and rapidly obtained. Obtaining reliable and useful measurements requires the use of accurate and dependable equipment, consistent and proper measuring techniques with precise plotting of those measurements. Although accurate anthropometric measurements provide valuable information this is an area where accurate assessment is often missed.

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SOMETHINGS NOT QUITE RIGHT--THE PROCESS BEGINS

The point at which the physician or other primary care provider becomes involved with the special needs of a family may vary. Some children enter your practice at risk due to birth trauma or prematurity, other children may experience injury as young children, and still other children may fall behind in development over time. In all of these cases there comes a time when you or the parents come to the realization that something isn't quite right.

The realization that something may be wrong can come to the parents and provider simultaneously, or it may not. If the primary care provider and parents don't share a common concern, this may interfere with the monitoring and evaluation process. It might even compromise trust between the parents and provider. Pay close attention to the nature and beginning of the process as it may effect the outcome.

Consider these four scenarios for beginning the process of investigation.

#1 The Physician and Parents Have a Low Index of Suspicion
Hopefully, this means that the child is developing normally. Routine monitoring and well child supervision is indicated.

#2 The Physician's Index of Suspicion is High, the Parent's Low
It is important to inform and educate parents about your concerns before you attempt any intervention. If you pursue further evaluation or treatment when parents don't share your concern, than you may encounter resistance and noncompliance.

Parents need to know about your concerns early. This period of investigation can serve as a valuable part of the acceptance process. A common reaction to overwhelming or difficult news is denial.

#3 The Physician's Suspicion is Low, the Parent's High
Parental observations and concerns can be the physician's most valuable asset in monitoring a child's progress. Parent's are usually highly accurate in estimating their child's development.

If you find yourself in this position, remember the potency of your role as a physician. Parents may fail to voice their concerns if they feel you are unreceptive. They may even resent you later if problems are confirmed.

#4 Physician and Parents Have a High Index of Suspicion
When parents and physician share a common concern this is the ideal place to begin. Starting the process from any other position may compromise future interactions or treatment plans.

BREAKING DIAGNOSTIC NEWS

Breaking diagnostic news may be the most difficult aspect of medical practice. It is important to relay complete and accurate information about the child in terms that the family understands. Relaying this information in a supportive manner, that does not alienate the family, requires skills and a level of comfort learned only through experience. It is not uncommon for medical professionals to receive little or no training in this area. Feelings of inadequacy or discomfort on the part of the medical professional may be misinterpreted by the family as a lack of caring or a reluctance to provide information.

"Be aware of the unique dramatic nature of the diagnostic meeting. Families will remember the moment in which it was presented. You may have diagnosed this condition many times, but for the family it is a unique and historic moment"

Just as there is no "typical" family there is no one "right" way to break diagnostic news to families. A common complaint of parents involves how their child's diagnosis was communicated to them. Frequently parents state they felt overwhelmed by medical jargon, or frustrated by limited or incomplete information. When breaking diagnostic news keep these simple considerations in mind.

BREAKING DIAGNOSTIC NEWS

- Be aware of the potentially devastating nature of this encounter
- Provide the family the most specific diagnosis
- Translate medical terms into lay terms that the family understands
- Provide complete information to the family
- Allow parents to express their emotions
- Touch the child or the parent

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DO'S AND DON'TS OF BREAKING DIAGNOSTIC NEWS

Just as there is no one "typical" family, there is no one "right" way to break diagnostic news to families.

DO: **Be aware of the potentially devastating nature of this encounter.** You may experience diagnostic news frequently, parents do not.

DO: **Provide the most specific diagnosis.** Give the diagnosis a name. Use appropriate professional terms. (Example: Down Syndrome instead of Mongolism).

DO: **Translate medical terminology into lay terms.** Explain what the diagnosis is and what it's implications are, as well as what it is not. (Example: Cerebral palsy is permanent damage to some part or parts of the brain that can cause delays in one or more areas of functioning, it does not necessarily include mental retardation).

DO: **Be aware of the emotional charge of words with negative connotations.** Clarify words like mental retardation and cerebral palsy be explaining them in behavioral terms. Avoid using them lightly, but do use them when appropriate. Also, remember that different words hold different meanings for different people. Use active listening or elicit feedback from the parent to find out how they are hearing things. Example: "What does __ mean to you?" or "It sounds like you're feeling __."

DO: **Provide complete information.** Parents report feeling lost and helpless upon hearing that their child has special needs. Knowledge is power. You empower parents by sharing information. Help parents deal with diagnostic news by making sure they understand their child's condition and what they can do to help their child.

DO: **Tell both parents together.** Parents need each other now more than ever. Both parents need to understand their child's condition. Second hand information may be distorted. If both parents can't be present it may be helpful to have another family member or friend present. Someone may even want to take notes.

DO: **Make sure parents leave with a list of available resources.** Parents are taking their baby home and need to be able to take care of their baby's daily needs. Parents need to know where to go to get the help they need. Linkage with parent support groups is very important.

DO: **Provide written material about the diagnosis.** Parents need time to absorb the information you have given them. You may have to repeat information at subsequent visits. Written materials can help parents answer questions that come up later. Do not let written materials take the place of talking directly to the family.

DO: **Let parents express their emotions.** Parents may need to cry, to express grief or anger, etc. Let parents know that you understand this and encourage them to express their feelings. Don't judge them or try to talk them out of their feelings. A brief touch or comforting response will be most helpful. ("I don't know how you're feeling, but I know this is very difficult.")

DO: **Touch the parent.** Touch is an effective non-verbal means of communicating concern and caring to the family.

DO: **Touch the child.** This is very important because your touch communicates to the parents your acceptance and interest in their child. Your example may even assist the family in their acceptance of the child.

DO: **Let parents have some hope.** Encourage a realistic outlook, but don't discourage parents from finding reasons for keeping a positive attitude. It is the parent's job to hope.

DO: **Have the nurse present if appropriate.** If she knows what the parents have been told then she can support them accordingly. The nurse may be the only one around later when the parents have additional questions. Example: "Did the doctor say my baby has a hole in his heart?"

DO: **Talk with parents about the effect on other family members.** Parents will often have concerns about how to tell family and friends. Assist parents with a simple, accurate explanation that they can use when telling others.

DON'T: **Withhold positive or negative information.** This will result in parents resenting you later.

DON'T: **Feel that you have to have all the answers.** Parents will respect you and trust you if you say "I don't know, but we'll find out."

DON'T: **Withhold concerns about their child.** Parents tell us that they would rather know when you suspect a problem. If follow up testing reveals that there is no problem they will be impressed with your thoroughness and grateful for the positive outcome. If there is a problem, the period of investigation will allow parents time to take valuable steps forward in the acceptance process.

DON'T: **Be angry if the parent repeatedly asks the same questions.** Selective hearing and forgetting are not uncommon for people in crisis or under extreme stress.

Why Should Educators Participate in Family-Centered, Community-Based, Coordinated Services?

Educators are advocates for children. Classroom teachers, school administrators, and other school personnel face the daily challenge of meeting the educational needs of all children and adolescents. This includes children with disabilities, learning problems, behavior problems, chronic conditions, health problems, and children at risk.

Advances in medical knowledge and technology have led to decreased early childhood mortality and have allowed more children with disabilities and complex medical problems to lead more functional and normal lives. These medical advances, in conjunction with public education laws (that entitle every disabled child to a free, appropriate public education in the least restrictive environment) have placed new demands on schools. Many children with special health care needs may not qualify for special education or related services but they still require planning and intervention to maximize their educational experience. School health services must be adequate to meet the requirements of special needs children while they are in school.

Biological and environmental factors also impact upon every child's potential for learning. It may be difficult to meet a child's educational needs without also addressing medical, health, and social needs. Health care providers, human service providers, and parents should enhance the educational process.

Children spend a majority of their waking and learning time in school. If the community-based care of children with special needs is to be successful, schools must be part of the equation. Educators are vital members of the community based team that develops comprehensive services for children with special needs.

What Does It Mean To Have A Chronic Health Condition or Disability?

When my oldest daughter was only 4 she told me this about her Aunt Rene who has severe cerebral palsy and is mentally retarded, "Rene isn't able to grow up. She has a broken arm and leg that will never get better."

Most of us think of health problems or illness as temporary. It is something that troubles us until we "recover" or are "cured". For many students this concept needs redefining. Students with chronic health problems or disabilities and their families live with a daily health concern or disability--one that may last a lifetime. For these children to be as healthy as possible does not mean recovery or cure, but management and control. Our efforts should be directed at helping the child and family accomplish this goal.

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What Is The Role of The Educator?

One of the goals of education is to foster good health. Health topics are taught in all Wyoming school districts, with emphasis on both physical and mental health.

As an educator how do you promote a child's health when that child has a chronic illness or a disability? The first step is to recognize that some educational needs cannot be adequately addressed without also considering the child's medical and social needs. This includes knowledge of the child's medical history, current health status, current neurologic and developmental status, current medications and treatments, medical concerns, and medical recommendations. The child's primary care physician can provide this information and can assist school personnel in making appropriate modifications to the child's educational program. In return, school personnel can assist the physician by providing pertinent information on the child's physical and social behavior based on their observations. The school nurse serves as a link between the medical and educational communities and can assist in coordinating services between the health care provider, the school and the family. The school social worker can help assure that the child's psychosocial needs and family support issues are being adequately addressed.

Your knowledge of the public education laws will also help you understand the entire service delivery system, ensure the protection of civil rights, and improve collaboration with other agencies and families. Everyone plays a part in making the full intent of public education laws a reality. Participating on the community based team ensures fair distribution of responsibility and allows all providers the opportunity to pool knowledge and resources. Educators are in an ideal position to take a leadership role in this process.

Classroom Teachers Are "Primary" Observers:

All members of the community-based team depend on classroom teachers as the primary observers of students' daily behaviors at school. The classroom teacher is in an excellent position to note changes in a student's health, behavior and overall school performance. Specialists in education and health need to recognize and reinforce the pivotal role of classroom teachers. Specialists can provide inservice training and consultation to sharpen classroom teachers' observation skills. They can help improve teachers' abilities to identify behaviors of concern and to resist premature labeling or diagnosis of underlying problems. The better the observation, the speedier and more efficient the assessment, diagnosis and intervention.

The team depends on accurate information when planning services for the student with a chronic health condition or physical disability. Teachers are instrumental in this planning process and can:

1. provide information that is based on daily observations
2. document observations in writing
3. collaborate with the school nurse to review the child's health history and current health status to assure that health factors are considered

Classroom teachers should not dismiss their concerns as foolish or assume that any child having special needs has previously been identified. Many children are not identified as having special needs prior to school age. This may be due to the fact that many children do not receive routine health care, or for a variety of reasons parents have failed to follow through with previous recommendations. The classroom may be the first opportunity any professional has ever had to observe a child on a consistent basis.

Teachers and Other School Personnel Should:

1. Identify and refer children with special needs
   a.) work with the Developmental Center and Headstart programs in your area to facilitate transition of children at school age
      - their experience with the child and family can be very helpful when planning services and interventions
      - oftentimes these children won't qualify for special education services but they still require specific interventions
   b.) be knowledgeable about "child find" activities in your school
   c.) each school district has child identification, referral and evaluation procedures in place (you have the right to access these services)
   d.) refer any child you suspect may have a disability to the Child Find Coordinator or appropriate person within your school
   e.) refer all children with medical needs to the school nurse
   f.) consult with other school personnel (school nurse, social worker, special education teacher) if you feel it is indicated
   g.) follow-up on your referral
2. Increase your knowledge and skills to properly identify children with special needs
   a.) learn more about normal growth and development, learning disabilities, chronic conditions, specific health problems, factors that place children at risk, etc.
   b.) work with other staff members to plan inservice activities
      - utilize the expertise of existing staff (special ed teachers, school nurse, school social worker, etc.)
      - invite community providers to share their knowledge and expertise
   c.) talk directly with parents if you have specific concerns (this may seem threatening at first but gets easier with experience)
      -express your genuine concern for their child
      -remember most parents are receptive
      -parents may share the same concerns
3. Consider the needs of families who have children with complex health care needs
   a.) consult with the school nurse (be knowledgeable about the child's diagnosis, medications, special equipment, what to do in a medical emergency, etc.)
   b.) give parents the opportunity to discuss their concerns
   c.) participate in planning to accommodate the child's school health needs (remember many of these children do not qualify for special education services)
4. Participate in the IEP process if the child qualifies for special education services
   a.) your daily observations and interactions with the child make your input valuable
   b.) consider all aspects of the child's care (educational, medical, social) when planning services
   c.) consider the child's long range needs and plan for transition
5. Refer families to appropriate community programs and services
   a.) improve your knowledge of community programs and services
   b.) learn how to access services
   c.) invite area service providers to staff meetings
6. Become effective advocates for children and families:
   a.) make a personal commitment to improve services and outcomes for children and families
   b.) participate as a member of the community-based team

The Role of Child Care Providers

Over 60% of Wyoming children under the age of 6 are in child care or early education services (with the majority of these children in the care of home providers). These services are provided in a variety of settings by individuals who have diverse credentials, training, and experience. This includes early childhood specialists, preschool providers, day care providers, in-home child care providers and center-based child care providers. These providers routinely express common concerns, needs and experiences when working with children with special needs and their families. (In order to simplify this section, this group will be referred to as child care providers.)

Child care providers care for and observe infants and young children on a regular basis. Their observations, experience and knowledge make child care providers an excellent resource. Child care providers might be the first providers to suspect that a child has special needs. This is often in the areas of learning disability, developmental disability, speech and language delay, hearing impairment, attention deficit hyperactivity disorder, diabetes, etc. Child care providers need to know how to discuss concerns with parents, provide information on resources and participate in the implementation of recommended interventions. Child care providers have the opportunity to work with and support families in many ways--this is especially true when a child has special needs.

The child care provider's experience with the child and family should not be overlooked when the child makes a change to a new setting. The child care provider plays an important part in facilitating transition. This is extremely important when the child reaches school age. Developmental Centers, Headstart Programs and pre-schools should all be working closely with local schools in the area of transition planning. If this is not already occurring in your community this activity should be encouraged because it greatly benefits the child.

Another issue facing child care providers is compliance with the Americans with Disabilities Act. Child care providers must now include children with disabilities in child care settings. Some providers already provide services for children with disabilities but the majority of providers will need training and support in this area if the full intent of the law is to be realized.

All of these things pose new challenges for child care providers. If child care providers are to meet these challenges they should: participate in continuing education opportunities, increase knowledge of normal growth and development, network with other child care providers, become more familiar with the special education laws, learn to identify factors that place children and families at risk, and learn more about local early intervention services, other local programs, support groups, and child identification activities. Including child care providers as members of the community-based team assures that the needs of child care providers will be considered when developing a comprehensive system of care for children with special needs.

Why Learn About the Public Education Laws?

Traditionally the medical community and the educational community have looked at the child with special needs independently and planned services with little knowledge or understanding of the other. Differences in terminology, training, assessment, and treatment modalities can cause barriers between these two disciplines. The behavioral or physical implications of a possible or diagnosed medical condition are sometimes overlooked when planning educational services for a child. Parents frequently express frustration and concern over this lack of communication. They realize the ultimate benefit that information sharing between the educational and medical communities would have for their child.

It is important to keep in mind that many children with special health care needs do not qualify for special education services. Schools are still responsible for meeting the needs of these children while in school. As more children with complex medical problems enter school, schools will be called upon to provide more health related procedures and interventions. Collaboration between the family, the school and health care providers is essential to meet the needs of children with special health care needs.

This section of the notebook is designed to familiarize you with the special education laws, assessment and eligibility criteria, and advocacy within the educational system.

The public education laws require that a free, appropriate public education be provided for all children with disabilities. These laws provide health agencies and medical providers the opportunity to assist in the development of a comprehensive system of services. Although not all children with special health care needs require or qualify for special education services all children will benefit from the development of a family-centered, community-based, coordinated system of services.

The Education for All Handicapped Children Act (PL 94-142) and its subsequent amendments represent the most important pieces of educational legislation in the history of educating children and youth with disabilities. These laws have brought about sweeping changes in the requirements to provide special education services for children with disabilities, and made services more accessible.

PL 94-142
Education for All Handicapped Children Act
* passed in 1975
* entitles children with disabilities 5 to 21 years of age a free public education

PL 99-457
Education of the Handicapped Act
* passed in 1986
* mandates that services be extended to children 3 to 5 years of age with disabilities
*provides funds for states to offer early intervention services to children with disabilities birth to age 3

PL 101-476
Individuals With Disabilities Education Act
*passed in 1990
*the special education laws are now referred to as IDEA

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Individuals with Disabilities Education Act (IDEA)

This is the 1990 reauthorization of the original PL 94-142. The law says that all children with disabilities have the right to an education that is free, appropriate and includes special education and related services to meet each child's unique needs.

IDEA also adds a new component to the child's Individual Education Plan (IEP); the transition plan. Beginning no later than age 16, each student must have a statement of the transition services that he or she needs in order to prepare for such postschool outcomes as employment, postsecondary education, adult services, independent living, and community participation.

Transition Services

According to the Wyoming Department of Education, transition is a coordinated set of activities for a child, designed within an outcome-oriented process, which promotes movement from school to post-school activities. This can include postsecondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, and community participation. The coordinated set of activities is based on the individual child's needs and can include instruction, community experiences, the development of employment and other post-school adult living objectives, and when appropriate, acquisition of daily living skills and functional vocational evaluation.

IDEA requires that those involved in transition planning address not only the employment future of students with disabilities, but also their future needs within the much broader focus of life within the community. The new transition planning addresses the problems that many former special education students have expressed in: finding or keeping employment; poorly integrating into the community; lacking social networks; lacking independence; and difficulty accessing appropriate adult services, post- secondary education and training programs. Transition services are now a required component of the child's IEP starting at age 16, or younger, if appropriate.

Providing transition services requires a coordinated set of activities. Schools must develop partnerships with the community, adult service agencies, employers and parents to assure the successful transition of students to adult life. This requires a team approach.

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What Are Special Education and Related Services?

Special Education is specially designed instruction, that is provided at no cost to the family, to meet the unique needs of a child with disabilities. This might include classroom instruction, physical education, home instruction, instruction in hospitals and institutions and related services. The term also includes vocational education, if it consists of specially designed instruction, to meet the unique needs of a child with disabilities.

Related Services means supportive services determined necessary for a child with disabilities to benefit from special education. These services must be funded by the school system and might include: counseling, physical and occupational therapy, audiological services, speech therapy, psychological services, transportation, etc.

Medical Services as a Related Service

Medical services for diagnostic or evaluation purposes must be paid for by the school system if these services are considered necessary by the Multidisciplinary or IEP Team to determine a child's medically related handicapping condition.

School Health Services

Schools are now being called upon to provide some services that, in the past, were considered medical services. This is due to the fact that more children with complex medical needs are now in school. Physicians will increasingly be called upon by school systems to consult on children requiring catheters, oxygen, central venous lines, gastric feeding tubes, ostomies, etc. In many cases these children are well enough to attend school if the necessary nursing support is available. If a medical service is determined necessary for a child to benefit from his education and this service can be readily performed by a school nurse, trained lay person or medical para-professional then the school can provide this service. You may find this information helpful as you look for avenues to provide comprehensive services for the children under your care.

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REHABILITATION ACT OF 1973-SECTION 504

The Office of Civil Rights is responsible for overseeing compliance with Section 504 of the Rehabilitation Act of 1973. The definition of a disability is broader under Section 504 than under IDEA. Services can be provided for a child under Section 504, even though the child may not qualify for services under IDEA. Children with special health care needs frequently receive necessary services under Section 504 or under the Americans With Disabilities Act.

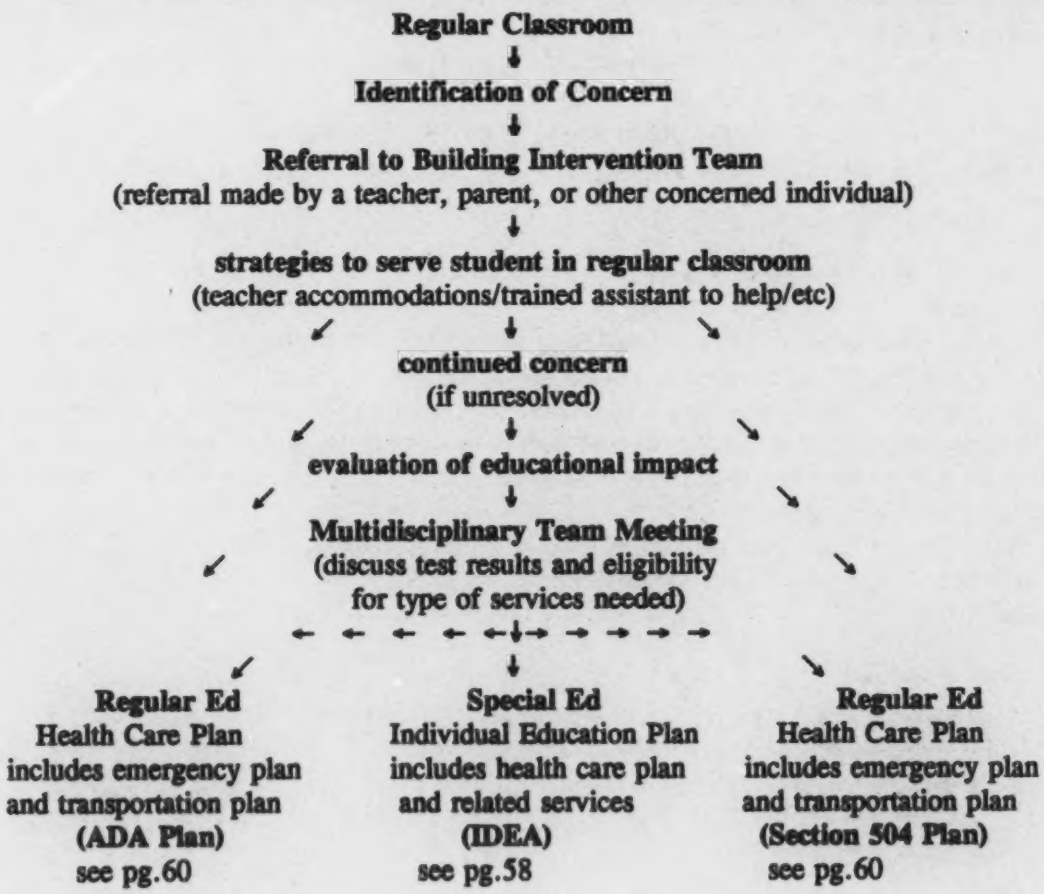
Section 504 compels a school district to make "reasonable accommodation" for children with disabilities in order to enable them to participate in and enjoy the benefits of education programs and activities.

AMERICANS WITH DISABILITIES ACT OF 1990

Known more commonly as ADA. The law gives civil rights protection to individuals with disabilities that are like those provided to individuals on the basis of race, sex, national origin, and religion. It guarantees equal opportunity for individuals with disabilities in employment, public accommodations, transportation, state and local government services, and telecommunications.

There is no active enforcement in the law. Individuals may file a complaint with a designated agency or bring private lawsuits.

Process Options For Providing Needed Services For Children With Special Health Care Needs Through The Public School System



Components of the Individual Health Care Plan

- description of condition
- source of medical care
- health problems list
- description of illness/condition
- specific precautions
- health care treatment plan
  - -includes schedule, personnel trained, procedures, and written authorization
- emergency information
  - -person to contact
  - -back-up plan
- transportation plan
- re-evaluation date

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CHILD FIND SERVICES

Under IDEA school officials are required to provide some type of public awareness campaign or service to inform parents of the availability of services for infants, toddlers, preschoolers, and school age children with disabilities. Every school district in Wyoming is required to have a Child Find Coordinator to run the Child Find Program.

Where and What Is Child Find?

- every school district and developmental center must have a Child Find system
- to identify, locate and evaluate every child suspected of having a disability, birth through age 21

Who Can Refer A Child To Child Find Services?

- parents, teachers, physicians, or other individuals who suspect that a child has a disability
- written consent must be obtained from the parents prior to evaluation

The Child Identification Coordinator

- each school district and regional developmental center appoints a Child Identification Coordinator
- the coordinator develops and implements an ongoing system to locate, identify and evaluate children suspected of having disabilities
- this includes a process for receiving and sending forward referrals from individuals or agencies

According to the **Rules and Regulations Governing Services for Children with Disabilities Wyoming Department of Education** the referral and evaluation process involves:

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Building Intervention Team

- each school district and regional developmental center establishes a building intervention team to receive referrals
- comprised of at least 2 school educational staff, and the principal or developmental center administrator
- must notify the parents that the child has been referred
- evaluates and documents pre-referral interventions (assures that hearing and vision screening have been completed in past 12 months)
- may make suggestions for the teacher to try with the child prior to referral for an evaluation
- refers children suspected of having disabilities for a multidisciplinary evaluation

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Multidisciplinary Evaluation

- within 10 days of referral a case manager is appointed who:
  - obtains written parental consent for assessment
  - develops an assessment plan
  - appoints a multi-disciplinary assessment team to conduct the assessment
- multi-disciplinary assessment
  - completed within 45 days
  - conducted at no expense to parents
  - administered by trained personnel
  - culturally fair
  - tests are considered valid for the purpose for which they are being used
  - examines abilities and all areas of suspected disability
  - a written report on the results of the assessment is completed and sent to the IEP Team or the Child Study Committee

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Individual Education Plan Team

- determines the child's eligibility, placement and need for special education and related services

PUBLIC LAW 99-457

PL 99-457 was passed in 1986. This law requires that, by 1992, every state provide a free and appropriate public education and related services to all disabled children starting at age three. The intent of PL 99-457 is to enhance child development from the earliest years, decrease the need for special education when the child reaches school age, and to offer support to families.

PART H OF PL 99-457

Part H, the Handicapped Infants and Toddlers Program, makes funds available for states to provide early intervention services to children birth to age 3. Part H is not mandatory, however Wyoming elected to participate in this portion of PL 99-457. Part H recognizes that accepted concepts of special education for older children are too narrow for infants and toddlers.

Part H requires that each state must have a statewide interagency council in place by the fifth year of participation in the program. This gives states the opportunity to implement the law to meet their particular needs. In Wyoming the Early Intervention Council, with its members appointed by the Governor, fulfills this requirement of Part H. Parents of children with disabilities are also members of the Council.

The intent of PL 99-457 is to expand the view of early developmental support. It provides states with a unique opportunity to forge an early childhood system that brings together medical, educational, developmental, and social services. Under Part H services are also extended to the family to assist them in the development of their child.

Full implementation of this law serves to enhance and strengthen all efforts to develop a family-centered, community-based, coordinated system of services that will benefit all children. We all play a part in making such a system a reality.

Early Intervention Services Include:

1. therapy
2. special instruction
3. family training
4. case management
5. health services

Part H requires that every child (birth to age three) suspected of having a disability receive a comprehensive, multi-disciplinary evaluation to assess the child's strengths and needs, and to determine the family's ability to nurture their child. Based on this information, a plan of early intervention services, called the Individualized Family Service Plan, (IFSP) is developed. The plan must be reviewed at least annually. The plan of services must not only meet the needs of the child but also the unique needs of the family. The developmental centers across the state are required to develop an individual family service plan for every child (birth to age three) that they serve. An Individual Education Plan (IEP) must be developed by the developmental center for all children 3 to 5 years of age.

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INDIVIDUAL FAMILY SERVICE PLAN (IFSP)

- must be developed for any child birth through age 2 eligible for early intervention services
- states what services are required to meet the needs of the child and family
- designates a family service coordinator or case manager

Designating a family service coordinator or case manager is now a requirement of the Individual Family Service Plan. This service is offered to the family at the time the IFSP is developed. Although it is not required that the family service coordinator be an employee of the developmental center, this is usually the case. Families have the right to refuse this service, but rarely do so. Parents may serve as their own case managers and occasionally do so.

In order to adequately provide case management services open communication and collaboration must exist between agencies and providers. Your willingness to provide information and maintain communication with the developmental centers will enhance their efforts. You may find that you come to rely on this service to assist you in your efforts to provide optimal care.

The ultimate goal of case management is to assist families to gain skills and independence in problem solving, management of the human services system and self advocacy.

WHAT SHOULD YOU EXPECT FROM EARLY INTERVENTION PROGRAMS?

- that they provide developmentally appropriate experiences
- provide services that are tailored to meet the needs of the child and family

DIVISION OF DEVELOPMENTAL DISABILITIES

The Division of Developmental Disabilities, within the Wyoming Department of Health, has been designated by the Governor as the lead agency responsible for providing services for infants and toddlers with disabilities. It has also been designated as an Intermediate Education Unit (IEU), subject to the general supervision of the Wyoming Department of Education, to oversee the provision of special education and related services to preschoolers with disabilities. These services are provided by independent nonprofit developmental centers in 14 service regions across the state.

Wyoming Eligibility Criteria (birth through 2 years)

Infants and toddlers qualify for early intervention services when they are experiencing developmental delays in one or more of the following areas:

1. **cognitive development**
2. **physical development including vision and hearing**
3. **language and speech development**
4. **psychological development**
5. **self-help skills**
6. **diagnosed physical or mental condition that could result in developmental delay**

For the child to qualify for early intervention services 1.5 standard deviations or a 25% delay in one or more developmental areas must be documented. The deviation and percentage of delay are not equivalent measures. Qualification can also be based on clinical opinion if there are no standardized measures or procedures that are appropriate for the child's age. Early identification and referral to early intervention services rely heavily upon the observations and knowledge of primary care physicians and other primary care providers. Item 6 allows a child to receive services based on a diagnosis that has a high probability of resulting in delay. This means that no delays or lags in development have to be observed in order to qualify for services under condition number 6.

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Public Law 94-142, Education for All Handicapped Children Act, passed in 1975 required all states to provide a free appropriate public education to school aged children with disabilities. In 1986 PL 99-457 amended the original law and extended the rights given under PL 94-142 to all children with disabilities starting at age 3.

HIGHLIGHTS OF PL 94-142

1. **Individualized Education Plans**
2. **Free appropriate public education regardless of the disability (ages 3-21 years)**
3. **Least restrictive environment**
4. **No exclusions from public education programs**
5. **Parents are to be active participants**
6. **Due process rights**

It is important that health care providers be aware of the key provisions of the special education laws. Many of the children that you see will require special education services in order to succeed in school. Your knowledge of the special education laws will allow you to serve as an advocate for the child and family within the educational system.

1. Individualized Education Plan (IEP)

An Individual Education Plan is developed for any child three through 21 years of age who qualifies for special education services. Individual evaluations, conducted by a multidisciplinary team, are required for every child receiving special education services. The IEP is developed by the IEP Team (sometimes called the Child Study Committee). The IEP Team must include the child's parents or guardians and others concerned with the child's welfare.

IEP Team

- develops the child's Individual Education Plan (IEP)
- may include the child's parents, school officials, evaluators, the child's regular education teacher, and other concerned individuals requested by the parents or school
- determines what services will be provided
- determines where services will be provided (least restrictive environment)
- reviews and revises the IEP at least annually

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Individual Education Plan (IEP)

The IEP allows for the integration of medical, health and social issues into the development of a comprehensive education plan.

- is developed for any child 3 or older eligible for special education services
- describes the child's present level of educational performance including academic, motor, social, vocational, and self-help skills
- annual (long-term) goals and short-term objectives
- specific special education and related services to be provided
- how much the child will participate in regular education programs
- how often and how long the child will receive special education and related services
- whether or not extended school year services are needed
- how it will be determined if the child is achieving the goals and objectives
- the type of diploma that will be issued if the child is in secondary school
- transition services (such as vocational goals) are addressed if the child is 16 years old or younger, if appropriate
- reviewed on an annual basis

The IEP meeting is very important because it serves as a communication vehicle between parents, other interested parties and school personnel. All pertinent parties can participate in developing the IEP. They jointly decide the child's needs, what services will be provided to meet those needs, and desired outcomes. The IEP process also can provide an opportunity for resolving differences between the parents and the school.

2. Free Appropriate Public Education (FAPE)

This means that special education and related services are provided at public expense, without charge to the family and the services must be appropriate. The term appropriate is vague and often causes disagreement between parents and school officials. Over the years numerous court cases have helped determine the meaning of appropriate, and will continue to do so over time. At this time an educational program is considered appropriate if it confers "some" educational benefit to the child; there is no requirement to maximize the child's potential. On the other hand a program that only prevents regression or provides trivial educational advancement is not enough. As you can see, these findings leave room for a great deal of interpretation as to what is appropriate. The input that you can provide through your knowledge of a particular child's capabilities and limitations will be instrumental in developing a program that is appropriate for that child.

"Appropriate" refers to educational programming and placement.

- **Programming**
  - the special education and related services that will be offered to a child
  - is determined by the IEP Team and is written into the child's Individual Education Plan

- **Placement**
  - the type of classroom, school or facility in which the child will receive special education and related services
  - is determined by the IEP Team and is written into the child's Individual Education Plan

Programming and placement of any child with a disability must be in the least restrictive environment. This is the next requirement of PL 94-142.

3. Least Restrictive Environment (LRE)

This means that to the maximum extent appropriate children with disabilities are educated with children without disabilities. Education in a regular classroom, with modifications for children with disabilities, is often considered to be the least restrictive environment for providing educational services. This has been called mainstreaming; it is also called inclusion. Although inclusion is desirable, it is not always possible depending on the child's needs.

For educators, placement of the child is the end result of the IEP process. Child protection or family service workers frequently see placement of a child as the first step, or the point where a child enters their system. Once the child is placed, and out of immediate danger, then their planning process begins. This can cause some confusion when these two disciplines work together.

Educational Programming and Placement in the Least Restrictive Environment

- To the maximum extent appropriate special education and related services must be provided in the least restrictive environment
- Mainstreaming is considered the least restrictive environment
- Mainstreaming can mean education in a regular classroom or in regular education activities with modifications for children with disabilities
- Mainstreaming requirements are balanced against the child's need for a more structured environment

According to the Rules and Regulations Governing Services for Children with Disabilities, Wyoming Department of Education, each public agency ensures that a continuum of alternative educational placements is available at all times to meet the needs of children with disabilities. This includes:

1. **Regular Environment** is the placement for children with disabilities who are in the regular class (school-age) or regular environment (preschool age) 80% through 100% of the school day. This may include:
   a.) regular class with special education and/or related services provided within the regular class
   b.) regular class with special education and/or related services provided in another setting

2. **Special Environment** is the placement for children with disabilities who are in the regular class (school-age) or regular environment (preschool age) for 40% through 79% of the school day. This may include:
   a.) special education classrooms with special education and related services provided in another setting; and part-time participation in a regular classroom
   b.) special education classrooms with part-time instruction in a regular class

3. **Separate Class Environment** is the placement for children with disabilities who are in the regular class (school-age) or regular environment (preschool-age) for 1% through 39% of the school day. This may include:
   a.) special education classrooms with part-time participation in a regular class; or
   b.) special education classrooms full-time in a regular school building

4. **Separate School Environment** is the placement for children with disabilities who receive special education and related services in a separate facility for children with disabilities within the jurisdiction of the Local Education Agency or preschool attendance center

5. **Residential Environment** is the placement for children with disabilities who receive special education and related services in a residential facility for students with disabilities outside the Local Education Agency or preschool attendance center.

6. **Homebound or Hospital Environment** is the placement for children with disabilities who receive special education and related services at home or in a hospital.

4. No Exclusions

Guarantees that all children with disabilities receive a free appropriate public education regardless of the severity of the disability. The unavailability of programs or the lack of funds is no exception to providing services. A child does not have to demonstrate an ability to benefit from educational services in order to receive services.

5. Parents Are to Be Active Participants

Parental involvement is a hallmark of PL 94-142. The law recognizes that parents have a special insight into their children's needs and that children benefit when parents and educators work together.

Parents must give written consent prior to any evaluation for or placement in special education services. Parents are equal members of the IEP Team and participate in the development of their child's Individual Education Plan (IEP). Parents also have the right to involve others concerned with their child from outside the school in development of the IEP.

6. Due Process Rights

Allows parents a number of procedural safeguards:

- parents have the right to examine all relevant records
- parents have the right to obtain an independent evaluation of their child
- parents must be given prior written notice of changes in their child's programming or placement
- parents have the right to initiate mediation or an impartial due process hearing if a complaint exists regarding services for their child
- if the situation can't be resolved, any party has the right to bring civil action in any state or federal district court

Although parents have the right to an independent evaluation there is no requirement that the school must pay for this evaluation. Court cases have found that the school is liable for payment only if the school's initial evaluation is found to be inadequate or inappropriate.

The Wyoming Department of Education requires specific evaluation procedures, and eligibility criteria for each category of disability. The disability categories are:

DISABILITY CATEGORIES
(Age 3 to 21)

1. **Autistic disability**
2. **Deaf-blind disability**
3. **Developmental disability**
4. **Emotional disability**
5. **Health disability**
6. **Hearing disability**
7. **Learning disability**
8. **Mental disability**
9. **Orthopedic disability**
10. **Speech/language disability**
11. **Traumatic brain injury disability**
12. **Visual disability**

Developmental disability is a category available only to children age 3 through 5 years who meet the criteria. Once the child is school age they must qualify in one of the other disability categories to continue to receive special education services.

There is frequently confusion between medical providers and educators because the disability categories used by the Department of Education under IDEA are written to correspond with educational terminology and not medical terminology.

The following information is taken directly from the **Wyoming Department of Education (1992) Rules and Regulations Governing Services for Children with Disabilities Manual**. It gives a brief description of each disability category.

1. **Autistic Disability:** a disorder which significantly affects verbal and non-verbal communication and social interaction, generally evident before age three, and adversely affects educational performance; Characteristics of autism include irregularities and impairments in communication, engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences.
2. **Deaf-blind disability:** concurrent hearing and vision impairments, the combination of which cause severe communication, developmental, and educational problems.
3. **Developmental disability:** a significant delay in cognitive, social/emotional, communication, motor, or adaptive development that adversely affects the child's performance. Developmental disability is a category available to children ages three until the child enrolls in a public school program, who do not qualify in other categories, but meet the developmental disability criteria.
4. **Emotional disability:** behavioral or emotional responses which are so different from appropriate age, cultural or ethnic norms that the responses adversely affect the child's educational performance. The child exhibits these responses over an extended period of time in several settings, at least one of which is school-related. A child may have an emotional disability concurrently with other disabilities. Emotional disability includes schizophrenic disorders; it does not include a child who is socially maladjusted unless the child also meets the emotional disability eligibility criteria.

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5. **Health disability:** A chronic or acute health problem (such as asthma, epilepsy, juvenile diabetes mellitus, hemophilia, cystic fibrosis, sickle cell anemia, cardiac conditions, cancer, fetal alcohol syndrome, or AIDS) which adversely affect educational performance and substantially limits a child's major life activities (such as walking, speaking, breathing, and learning) or limits a child's strength, vitality, or alertness.
6. **Hearing disability:** an inability to hear, ranging in severity from mild to profound which adversely affects educational performance. This category includes deaf and hearing impaired children.
7. **Learning disability:** (school age) a disorder in one or more of the basic psychological processes involved in understanding or using spoken or written language which adversely affects educational performance. Learning Disability may include perceptual disabilities, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia when the child meets Learning Disability eligibility criteria. Although a learning disability may exist concurrently with other disabilities, a learning disability does not include children who have learning problems which are primarily the result of vision, hearing, orthopedic, mental, or emotional disabilities, or environmental, cultural, or economic disadvantage. Learning Disability is a disability category for school-age children only.
8. **Mental disability:** significantly sub-average general intellectual functioning existing concurrently with deficits in adaptive behavior, manifested during the developmental period, which adversely affects educational performance.
9. **Orthopedic disability:** a severe orthopedic impairment (to bone, muscle, or joint) which adversely affects a child's educational performance. This includes impairments caused by birth defects, disease or unknown causes (such as cerebral palsy, muscular dystrophy, juvenile rheumatoid arthritis, osteogenesis imperfecta, multiple sclerosis, osteomyelitis, missing limb, fractures, or burns that cause contractures, etc.)
10. **Speech/language disability:** a communication disorder involving an impairment in articulation (may include phonology or the sounds of speech), fluency, language (may include phonology), or voice, which adversely affects a child's educational performance. For specific definitions in each area of impairment, see eligibility criteria.
    Articulation Impairment. Articulation impairment means speech sound production or phonological errors atypical of a child of comparable age and development.
    Fluency Impairment. Fluency impairment means abnormal flow of speech evident in interruptions by repetitions or prolongations of sounds, syllables or articulary positions or by avoidance and struggle behaviors.
    Language impairment. Language impairment means a deficiency in language comprehension or production evident in the content, form, or use of oral communication or its equivalent.
    Voice impairment. Voice impairment means a significant deviation in pitch, intensity, or quality which consistently interferes with communication, draws unfavorable attention, adversely affects the speaker or listener(s), or is inappropriate for the age, sex, or culture of the child.
11. **Traumatic Brain Injury Disability:** an injury to the brain (trauma, aneurism, tumor) which impairs the child's cognitive function, physical or sensory abilities, communication, and/or social interactions. The impairment may be either temporary or permanent and causes partial or total functional, psychological or social/emotional adjustment problems which adversely affects education performance. The term does not include congenital or degenerative injuries or injuries induced by birth trauma.
12. **Visual Disability:** a visual impairment which, even with correction, adversely affects a child's educational performance. The term includes both blind and partially sighted children.

How Does IDEA Affect the Educational Rights of Children with AIDS?

There is no mention of AIDS in IDEA. AIDS in and of itself is not a disabling condition which is covered by IDEA. Since AIDS impairs the immune systems of infected persons, they often suffer from severe debilitating diseases. If the physical condition of a student with AIDS keeps a child from doing required classroom work or from learning in a regular school program, then IDEA mandates the provision of a free and appropriate education.

School officials have more than once attempted to totally exclude students from school who are infected with the AIDS virus. Such actions have been taken on the basis of state or local laws which require that students with infectious or contagious diseases be expelled from school; or based on genuine concern over the risk of transmission of the infection to other students. Court rulings have determined that the risk of transmission of the AIDS virus via the blood or saliva of an infected student was not significant enough to warrant total exclusion from the classroom. In one case, the court relied on the Rehabilitation Act of 1973 to rule that the student was "otherwise qualified," despite the presence of the AIDS virus, to participate in regular classes as a full-time student. The court also noted that the psychological harm that would be caused from exclusion from school outweighed the minimal risk of transmission of the AIDS virus to other students. School officials can be compelled to admit the student to school.

The School's Right to Discipline a Child With Disabilities

Frequently children with disabilities may experience behavioral problems that must be taken into consideration when planning special education services. As an advocate for the child within the educational system it may be helpful to know what authority school officials have to discipline children with disabilities.

1. If a student with disabilities has engaged in (or is likely to engage in) conduct which is disruptive, insubordinate, disobedient, destructive, or violent, then the student's conduct, and the school's response to such conduct should be addressed in the student's IEP.

2. Any disciplinary measures to be used must appropriately consider the nature of the disability and educational needs of the student.

3. If there is no relationship between a student's misconduct and his disability, the student may be disciplined under the regular policies applicable to students without disabilities.

4. If there is a relationship between misconduct and disability, the student may still be disciplined (including suspension for up to ten days), but the student cannot be expelled; instead the school must convene an IEP meeting to review placement and programming.

5. Discipline issues can be resolved by mediation or a due process hearing if the parents or guardians and school officials cannot agree upon placement or programming.

6. A school district may not expel a child from school if the child's parents or guardians have initiated legal proceedings regarding placement or programming ("stay put" provision).

EDUCATIONAL TERMINOLOGY

Public Law (PL) 94-142: Education of All Handicapped Children Act, passed in 1975, requires all states to provide a free appropriate public education to school aged children with disabilities.

Public Law 99-457: An amendment to PL 94-142 passed in 1986 requires states to provide a free appropriate public education to all children ages three through five years with disabilities. **Part H** provides funds for states to offer early intervention services to children birth to age three with disabilities.

IDEA (Individuals with Disabilities Education Act): A name change that resulted in 1990 when PL 94-142 and PL 99-457 were amended. It mandates that transition services and assistive technology services be included in a child's individual education program; and it creates a research and dissemination program on attention deficit disorder.

Section 504 (Rehabilitation Act of 1973): The Office of Civil Rights (OCR) is responsible for overseeing compliance with Section 504. The definition of disability is broader under Section 504 of the Rehabilitation Act than under IDEA. Parents may be able to obtain special education or related services for their child even though they may have been previously denied under IDEA. Section 504 does not require a student to be enrolled in special education to receive related services, under IDEA a student must be enrolled in special education to be considered eligible for related services.

Advocacy: To speak or write in favor of or on behalf of an individual or group.

Annual Review: Review of an IEP which must be conducted at least once every school year by the Child Study/IEP Committee. The IEP can be reviewed more often upon request.

Artistic/Cultural Therapies: are listed as "supportive services" and may include art, music and dance therapy. These programs assist the student with disabilities in developing abilities needed to benefit from the special education program. Dance therapy can improve posture, discipline, concentration, coordination, agility, speed, balance, strength and endurance. Art therapy provides students with a means of self-expression and creativity, and music therapy does the same. These programs provide students with social skills, perception, self-esteem and physical mobility and skills.

Assistive Technology Devices and Services: are not specifically listed in the law as related services, but are often provided as "other corrective or support services" necessary to help students with disabilities benefit from their education. An assistive device is any item, piece of equipment or product system which is used to increase, maintain or improve functional capabilities. The need for such supplementary aids and services must be included in the child's IEP.

At Risk: A term used with children who have, or could have, problems with their development that may affect later learning.

Board of Cooperative Educational Services (BOCES): Provides educational, vocational, and residential services to mentally and multi-handicapped children across the state.

Building Intervention Team: A team usually consisting of the building principal, the student's teacher, and other professional who meet to review information on students who may be experiencing difficulty in school. The team may recommend interventions, monitor the implementation of interventions, and refer the student for a multidisciplinary evaluation, when appropriate.

Child Find: Program required by IDEA to identify, locate and evaluate children with disabilities birth to age 21 and to advise their parents of their rights to early intervention and special education services.

Consent: Written permission that must be obtained from the parent or guardian before assessment; initial placement in special education; or the disclosure of confidential information from the child's school records to unauthorized persons.

Counselling Services: are provided by school counselors who work with students to improve their self concept and to make changes in or develop control of behavior. The counselors also assist students in making choices for further education or exploring career alternatives. Counselors may identify and refer students for special education services, contact parents to secure permission for referral or testing, assist teachers and parents in understanding student's level of functioning and needs, and provide supportive counseling. The parents of a student with a disability may need counseling and training to understand their child's disability and how it may affect his or her future. Counselors can help parents understand the special needs and developmental differences of their child and provide parents with information about parent support groups, financial assistance resources and professionals outside the school system.

Developmental Disability: A significant delay in cognitive, social/emotional, communication, motor or adaptive development that adversely affects the child's performance.

Division of Developmental Disabilities: A division within the Wyoming Department of Health designated by the Governor of Wyoming to serve as the lead agency to provide services for children with disabilities from birth to age 5.

Educational Performance: Means any area of education that is affected including 1.academic areas (reading, math, communications, etc.) 2. nonacademic areas (daily life activities, mobility, etc.)

Evaluation: Means procedures used to determine whether a child has a disability and the nature and extent of special education and related services that the child needs. The term means procedures used selectively with an individual child. It does not include basic tests or screening procedures used with all children in school.

FAPE (Free Appropriate Public Education): Special education and related services are provided at public expense; special education and related services must meet the unique needs of the child with a disability and these services must comply with the child's Individual Education Plan.

IEP (Individual Education Plan): Is developed for any child three or older that is eligible for special education services. It describes the child's present level of developmental/educational performance; states short and long terms goals; and describes what services will be provided and in what setting.

IEP Team: Includes the child's parents, school officials, evaluators, and other individuals at the request of the parents or public agency; develops the IEP; determines appropriate placement and services

IEU (Intermediate Education Unit): Division of Developmental Disabilities (Wy Department of Health) has been designated as an IEU (subject to the general supervision of the Wy Dept of Education); responsible for providing identification, evaluation and services for children birth through age five with disabilities. The Division contracts with independent nonprofit developmental centers around the state within 14 service regions.

IFSP (Individual Family Service Plan): Must be developed for any child birth through age 2 receiving services under PL 99-457. It states the specific early intervention services required to meet the unique needs of the child and family. The family service coordinator is responsible for implementation of the IFSP and coordinating with other agencies.

LEA (Local Education Agency): or school district

LRE (Least Restrictive Environment): to the maximum extent appropriate the child with a disability is educated with children without disabilities (called mainstreaming).
Medical Services: considered a "related service" only by meeting specific conditions. They must be provided by a licensed physician to diagnose a disability, determine the need for special education and determine the necessary related services and they must be for diagnostic reasons, not including direct, ongoing medical treatment.

Occupational therapy: is a treatment program which concentrates on improving skills which help in activities of daily living. An occupational therapist will assess such skills as eating, dressing, writing, using utensils, and managing in the environment, then develop a treatment program to make improvements where needed. This therapist provides treatment to strengthen and develop fine motor and small muscle functions of the face, upper trunk, arms and hands, and helps the student improve in tasks necessary for independent functioning such as chewing, swallowing and eye-hand coordination. When provided as a related service by a school, occupational therapy is meant to enhance a student's ability to function in an educational program.

Physical therapy: focuses on gross motor skills which rely on the large muscles involved in physical movement and range of motion. The physical therapist provides treatment to increase muscle strength, mobility and endurance and helps to improve the student's posture, gait, and body awareness. A physical therapy treatment program may include manipulation, exercises, and therapy using heat, water, and light. The physical therapist may also monitor the function, fit and use of mobility aids and devices such as prosthesis and orthotics (artificial limbs and braces).

Placement: The physical location in which the child will receive the special education and related services described in the IEP.

Programming: The special education and related services that will be offered to a child in accordance with the IEP.

Psychological Services: are provided to students with disabilities to help them benefit from their education. The services may be in the form of counseling for administering and interpreting test, or observing student's behavior and assisting educators to create appropriate programs. A school psychologist who has special training in administering and interpreting tests and assessment procedures may be referred to as a diagnostition.

Recreation Therapy of Adaptive Physical Education: teaches students individual and recreation sports activities. The program can improve socialization skills, as well as eye-hand coordination, physical, cognitive and communication abilities. An Adaptive PE or Recreation Therapist will familiarize students with the leisure time activities available in their own communities and teach the skills necessary to participate in those activities, whether it be bowling, fishing, swimming or skiing.

Related Services: Those services which children with disabilities must receive in order to benefit from the educational process. Includes physical, occupational, and speech therapy; psychologic, audiologic, recreation, counseling, and medical services (for diagnostic or evaluation purposes).

School Health Services: If a medical service is determined necessary for a child to benefit from his education and this service can be readily performed by a school nurse, trained lay person or medical para-professional then the school can provide this service.

Social Work Services: address the whole welfare of a student with a disability. Problems at home or in the community can affect a student's performance at school, as can difficulties at school affect a student's life at home and in the community. A school social worker will prepare a social or developmental history for the student with a disability, provide counseling to the student and family, help solve problems in a student's living situation which are affecting the student's education, and mobilize school and community resources to enable the student to benefit from the educational program.

Special Education: Specially designed instruction (at no cost to the family) to meet the unique needs of a child with disabilities, including classroom instruction, physical education, home instruction, instruction in hospitals and institutions, and any related service. The term includes vocational education if it consists of specially designed instruction to meet the unique needs of a child with disabilities.

Transition Services: A coordinated set of activities for a child, designed within an outcome-oriented process, which promotes movement from school to post-school activities. The coordinated set of activities is based on the individual child's needs and can include instruction, community experiences, the development of employment and other post-school adult living objectives, and when appropriate, acquisition of daily living skills and functional vocational evaluation. Transition services are now a required component of the child's IEP staring at age 16, or younger, if appropriate.

Transportation Services: are provided to students who, because of the nature of their disability or the location of their residence, need special assistance traveling to and from school. Specialized equipment such as buses with lifts and ramps, travel in and around school buildings and travel to and from school is included under transportation services. Not all students with disabilities are eligible for specialized transportation services if they are able to use the same transportation as students without disabilities. A school district, in order to be in compliance with the law, cannot require families of students with disabilities, to assume the costs of those transportation services which are necessary to permit the students to benefit from their education.

Vocational Rehabilitation: A comprehensive federally funded program that assists individuals with handicaps in the areas of vocational assessment, counseling, training, physical rehabilitation, and job placement.

MEDICAL TERMINOLOGY

Acquired Immune Deficiency Syndrome(AIDS): A life-threatening disease due to markedly reduced lymphocytes and immunity. Pediatric cases are rare except for the offspring of affected adults, or children who have required multiple transfusions (hemophiliacs, for instance).

Amblyopia: Decreased vision or blindness.

Amenorrhea: The absence of menstrual periods. When regular periods stop, the most common causes are dieting, stress, or pregnancy.

Anemia: A low red-blood-cell count. While the causes are many, iron deficiency ranks first. A blood sample is needed to diagnose anemia.

Anorexia nervosa: In adolescents, excessive weight loss (more than 20 percent below ideal weight) and denial of being underweight. Over 90 percent are female. Psychotherapy is essential.

Apnea: An episode of cessation of breathing for 20 seconds or more, often associated with cyanosis (a bluish color of the lips). Apnea usually occurs in infants under 6 months of age. The causes are many.

Appendicitis: A blockage and infection of the appendix. The appendix is a blind pouch the size of your little finger that comes off the cecum (first part of the large bowel). Appendicitis gives constant pain in the right lower abdomen and requires surgical intervention.

Arthritis: Inflammation of a joint leading to pain, swelling, and limited motion. The causes are many.

Asthma: An allergic condition of the lungs. The smaller airways (bronchioles) go into spasm and become swollen with colds and when allergens or irritants are inhaled, leading to attacks of wheezing. Occurs in 5 percent of children.

Astigmatism: Distorted vision due to variations in refractive power on different parts of the cornea.

Attention deficit disorder (ADD) and Attention deficit hyperactivity disorder (ADHD): Occurs in 3% to 5% of children, most of them boys. A normal attention span is 3 to 5 minutes per year of a child's age. The child with ADD hasn't learned to listen when someone talks, wait his turn, complete a task, or return to a task if interrupted. 80% of boys and 50% of girls also have associated hyperactivity (increased motor activity) with symptoms of being restless, impulsive, and in a hurry (ADHD). 50% of these children also have an associated learning disability. The most common one is an auditory processing deficit (they have difficulty remembering complex verbal directions). However the intelligence of most children with ADD is usually normal.

Bell's palsy: An abrupt onset of weakness of the facial muscles on one side. Often associated with an ear infection, since the seventh (facial) nerve is damaged while traveling through the infected area. Usually clears in 1 to 4 weeks. Early treatment with steroids may be helpful.

Botulism: The most serious type of food poisoning. First symptoms are double vision, slurred speech, and swallowing problems. The cause is a toxin produced by bacteria in improperly canned vegetables. Contaminated food looks and tastes normal. During the first year of life, botulism germs can be acquired from swallowing dust or normal honey. Despite several studies, corn syrup has never been linked to a case of botulism. Progressive weakness (of suck, cry, and neck muscles) and constipation are the main symptoms in these babies.

Bronchiolitis: An infection of the bronchioles (small air passages) occurring in the first 2 years of life. The main symptoms are wheezing, rapid breathing, cough, runny nose, and fever. Usually caused by the respiratory syncytial virus.

Bronchopulmonary dysplasia (BPD): Lung damage that occurs in some prematures who needed mechanical ventilation for survival. Portable oxygen administration may be needed over the first 1 or 2 years until lung improvement occurs.

Bulimia: In adolescents, periodic food binging followed by self-induced vomiting or laxative-induced diarrhea to prevent weight gain. The weight, however, is usually kept in the normal range. Psychotherapy is essential.

Cellulitis: A spreading bacterial infection of the skin, often following a wound infection.

Cerebral palsy: Is a static encephalopathy. It is used as an inclusive term to describe a group of non-progressive motor handicaps due to brain injury either before or during birth.

Chlamydia: A germ that causes urethral or vaginal infections. Usually caused by sexual contact. Can also cause eye infections or pneumonia in newborns by contact at birth.

Chorea: Abnormal and unexpected muscle jerks. The location of the chorea changes. Sydenham's chorea is a type seen following rheumatic fever.

Chronic Fatigue Syndrome: A new disease with symptoms of extreme fatigue and sleepiness, muscle weakness, muscle and joint pain, confusion, memory loss, and eye pain lasting 6 months or longer. Probably due to a virus, but not infectious mono.

Cleft lip and/or palate: The incomplete closure of the lip and/or roof of the mouth. Can occur in various combinations. A birth defect of unknown cause. Requires surgical repair and speech therapy.

Clubfoot: A fixed (inflexible) deformity of the foot (usually downward and inward) present at birth. Requires repeated casts or surgical correction.

Congenital heart disease: A birth defect of the heart which is usually not inherited. The defects are of many types. Surgery is frequently required.

Conversion reaction: The sudden onset of a physical disability (e.g., paralysis or blindness) on an emotional basis. Commonly the youngster shows lack of concern (indifference) for the symptom. Also called a hysterical reaction. Requires psychotherapy.

Craniosynostosis: An early closure of the sutures (growth lines) of the skull. Surgery is required if multiple sutures are involved, and should be done before 6 months of age.

Cryptorchidism: An undescended testicle that remains in the abdomen. Needs to be surgically brought down into the scrotal sac by 2 years of age.

Cystic fibrosis: An inherited disease causing very thick mucus that blocks the lungs and pancreas. The main symptoms are recurrent pneumonia, diarrhea, and poor weight gain.

Diabetes insipidus: The inability to concentrate the urine, making the child predisposed to dehydration. Symptoms of increased drinking (polydipsia) and urination (polyuria). The causes are several.

Diabetes mellitus: The inability of the pancreas to produce insulin, leading to high blood sugar and sugar in the urine. The main symptoms are increased drinking and eating, excessive urination, and weight loss. The child needs daily insulin injections.

Diagnosis: The art or act of distinguishing one disease form another. A **differential diagnosis** is the term used when making a correct decision between diseases presenting a similar clinical picture.

Diphtheria: A serious bacterial infection of the throat with complications of suffocation, heart disease, and paralysis. Preventable with DPT immunizations.

Diplopia: Double vision. Caused by drug reactions, botulism, eye muscle or brain disease.

Down's syndrome: Newborns with Down's syndrome are mentally retarded, floppy, and have a characteristic facial appearance (mongolism). They are commonly the offspring of older mothers. Caused by an extra chromosome (Trisomy 21). Can be diagnosed during pregnancy by amniocentesis.

Encephalitis: An infection of the brain caused by various viruses. Also called sleeping sickness.

Endocarditis: An infection of the valves and lining of the heart.

Epiglottitis: A life-threatening infection of the tissues surrounding the vocal cords. The cause is the *Hemophilus influenza* bacterium. The epiglottis is the flap of tissue which normally covers the opening of the windpipe during swallowing and keeps food and drink off the larynx.

Epilepsy: A recurrent seizure disorder. The types and causes are many.

Exercise-induced bronchospasm: Attacks, lasting 20 to 30 minutes, of coughing and wheezing after (but sometimes during) exercise. Running in cold air is the main offender. Occurs in 10 to 20 percent of people (90 percent of those with asthma). Prevented by taking asthma medicine before sports.

Failure-to-thrive: A malnourished, underweight condition usually occurring during the first year of life. While the causes are many, in our country over half the cases are due to underfeeding (i.e., child neglect).

Fetal alcohol syndrome: FAS is a cluster of birth defects characterized by mental retardation, central nervous system dysfunction, facial abnormalities, and varying organ malformations. It is due to prenatal growth retardation caused by the woman's consumption of alcohol during pregnancy. Since there are no safe levels established for drinking during pregnancy it is recommended that a woman not drink during pregnancy. **Fetal alcohol effects: FAE are the more subtle** problems caused by a woman's consumption of alcohol during pregnancy. This includes: low birth weight, irritability and hyperactivity during the newborn period, short attention span, learning disabilities and behavioral disabilities which often don't appear until the child is older.

Fragile X syndrome: It is caused by an abnormal X chromosome, and it normally only seen males. Accounts for 25 percent of mental retardation in males. Features include a long face, large jaw, large testes, and scars from hand-biting. It can occur in females but it is less severe.

Galactosemia: An inherited enzyme defect that causes vomiting, diarrhea, liver damage, and mental retardation. Detection by newborn screening permits treatment with a galactose-free diet. Galactose is one of the sugars in milk.

Gastroesophageal reflux: The regurgitation or vomiting of food because the junction of the esophagus (food tube) and stomach doesn't close completely. The mild form is common in newborns and resolves by 1 year of age. The severe form can cause poor weight gain or vomited blood due to acid irritation of the end of the esophagus. This form may require surgery.

Giardia: A small parasite that causes diarrhea. Without treatment, the diarrhea can last for months.

Goiter: An enlarged thyroid gland, found in the front of the neck. The causes are many.

Gonorrhea: A bacterium that can cause genital infections. Spread by sexual contact. Eye infections of newborns are usually prevented by routine application of silver nitrate or antibiotic eyedrops.

Guillain-Barre' syndrome: An acute progressive symmetrical paralysis that starts in the feet and moves up the body over several days. Usually follows a viral infection. Some children need to be placed on a ventilator temporarily.

Heart murmur: A swishing noise heard over the heart. Due to turbulence in blood flow as it goes through the heart. While a murmur can be caused by heart disease, 99 percent are normal sounds (innocent or functional heart murmurs). Your physician can tell the difference. More than 50 percent of normal children have innocent murmurs.

Hemophilia: An inherited bleeding tendency due to the inability to produce certain clotting factors. Mainly occurs in males.

Hepatitis: A viral infection of the liver leading to jaundice (yellow skin), light-colored bowel movements, and dark-colored urine.

Hernia, inguinal: A bulging in the groin due to a hole in the abdominal wall. Requires surgery.

Herpes stomatitis: A viral infection causing multiple small, painful ulcers of the gums and lining of the mouth. Associated fever. Usually occurs in young children and doesn't recur (unlike fever blisters).

Hip, congenital dislocation: Being born with the hip out of the socket. A brace is needed for 3 months to correct the problem. Early diagnosis is important to prevent permanent damage.

Hydrocephalus: Blockage of spinal fluid flow out of the brain; resulting in a large head if not treated early. Treatment is a surgical shunt to drain the fluid to the abdomen.

Hydronephrosis: An enlarged kidney due to obstruction of its drainage system. Usually requires surgical correction.

Hyperopia: Farsightedness. Close objects are difficult to see.

Hypertension: High blood pressure. The causes are many in children. In adolescents, the cause is genetic (i.e., essential hypertension).

Hyperventilation: Rapid, deep-breathing attacks due to emotional stress. The symptoms include a sensation of smothering, dizziness, and tingling of the mouth and fingers. Occasionally proceeds to fainting. Quickly relieved by breathing into a paper bag or deliberately slowing down to 1 breath every 5 seconds.

Hypoglycemia: Low blood sugar with symptoms of hunger, headache, trembling, and sweating. May proceed to convulsions. Commonly overdiagnosed in our country.

Hypospadias: A birth defect in which the urethra opens onto the shaft of the penis rather than the end. Surgical correction is usually required.

Hypothyroidism: An underactive thyroid gland. When this condition occurs in newborns, it can cause very slow growth and development. Treated with thyroid medicine. Diagnosis before 6 weeks of age is important.

Idiopathic thrombocytopenic purpura (ITP): The most common bleeding disorder of childhood. Due to a temporary depletion of platelets (which are needed for clotting) following various viral infections.

Inborn errors of metabolism: Genetic diseases that involve the absence of a particular enzyme the body requires. Examples are phenylketonuria and galactosemia.

Infectious mononucleosis: A viral infection with fever, sore throat, swollen lymph nodes, and an enlarged spleen. Symptoms last 1 to 4 weeks.

Irritable colon of childhood: The most common cause of chronic diarrhea in infants. The loose, mushy stools do not interfere with normal weight gain. The cause is unknown but the condition miraculously clears at 2 1/2 to 3 years of age.

Kawasaki's disease: A disease of young children characterized by a red rash, red eyes, red mouth, enlarged nodes, and a fever lasting over 5 days. The cause is unknown. Over 20 percent of the children who get it develop heart disease. Early treatment with intravenous gamma globulin can prevent some coronary artery disease. Also called mucocutaneous lymph node syndrome.

Keloid: Overgrowth of scar tissue at sites of surgery or trauma. Some people have a tendency to produce raised scars. Plastic surgery can help.

Klinefelter's syndrome: In males, an extra X chromosome (i.e., XXY). Features include tall stature, borderline intelligence, breast development, small testes, and sterility.

Lactose intolerance: An inherited reduction in lactase, the enzyme needed to break down lactose in milk. Milk intake causes loose stools and gas. The condition is most common in dark-skinned races, and usually has an onset at 5 to 10 years of age.

Learning disabilities: Specific learning limitations (e.g., in mathematics or reading) in children of normal intelligence and motivation. Usually inherited. Illiteracy (the inability to read and write adequately to function in our society) is often due to untreated severe reading disability. Most schools have special programs to help these children.

Leukemia: A cancer of the white blood cells. With modern treatment, over half of children can be cured.

Malaria: A parasite transmitted by mosquitoes. Causes fever, shaking chills, anemia, convulsions, and coma. Affects over 200 million people worldwide and kills several million annually. The world's greatest cause of human disability. Could be eradicated if funds were provided. (Note:Doesn't occur in the United States.)

Mastoiditis: A bacterial infection of the air cells in the bone behind the ear. A complication of an untreated ear infection. Often requires surgery.

Meningitis: An infection of the meninges or thin membranes surrounding the brain and spinal cord. Usually caused by bacteria. Called aseptic meningitis when due to a virus.

Menorrhagia: Excessive or prolonged menstrual periods, often leading to anemia.

Mental retardation: An intelligence quotient (I.Q.) less than 70. Children with I.Q.'s over 50 can often learn to function independently. The causes are many.

Microcephaly: Small head size. Due to below-average brain growth. Extremely small heads are associated with mental retardation.

Migraine headaches: A headache that is incapacitating, throbbing, and on one side of the head. Nausea and vomiting are often present. Over 70 percent have a family history of similar headaches.

Minimal brain dysfunction (MBD): Twenty years ago, MBD was considered the main cause of attention deficit disorder, dyslexia, and other learning disabilities. Many physicians have discarded this simplistic, unfounded, and harmful label.

Mittelschmerz: Sharp lower abdominal pain on one side that occurs in menstruating women midway through their cycle. Lasts 1 to 2 days. Caused by small amount of blood or fluid contacting the abdominal lining when the egg is released from the ovary.

Muscular dystrophy: A group of genetically transmitted diseases. They are all characterized by progressive atrophy of different groups of muscles with loss of strength and increasing disability and deformity.

Myopia: Nearsightedness. Distant objects are difficult to see.

Nephritis: Kidney disease where blood is passed in the urine. The causes are many, but strep throat is one of the more common forerunners. Can become chronic.

Nephrosis: Kidney disease where protein is passed in the urine, leading to swelling (edema) of the face and feet. Often becomes chronic.

Neurofibromatosis: A dominant genetic disorder characterized by coffee-colored spots or benign tumors of the nerve sheaths (neurofibromas) or nerves (neuromas). Nervous system complications can occur. The disease is progressive in that distinctive features, may be present at birth but the development of complications is delayed for decades.

Osgood-Schlatter disease: A disease causing knee pain just below the kneecap on a small normal bump called the tibial tubercle. Occurs in adolescents and lasts 1 1/2 to 2 years. No permanent harm.

Osteomyelitis: A bacterial infection of bone.

Pelvic inflammatory disease (PID): A bacterial infection of the Fallopian tubes--often due to gonorrhea or chlamydia. Also called salpingitis.

Peptic ulcer: An ulcer of the stomach or duodenum which causes upper abdominal pain, vomiting, or bleeding.

Pericarditis: An infection of the sac that covers the heart.

Peritonitis: An infection of the lining of the abdomen. Usually caused by a ruptured appendix.

Pertussis: A serious bacterial infection of the windpipe and lungs. Also called whooping cough because coughing spasms often end with a high-pitched whoop. Preventable with DPT immunizations.

Phenylketonuria (PKU): An inherited enzyme defect that causes mental retardation, a light complexion, and seizures. Detection by newborn screening permits early treatment with a low-phenylalanine formula, followed by a restricted diet.

Pneumonia: An infection of the lungs. Generally not contagious.

Pneumothorax: A blowout of the lung leading to the escape of air into the space between the lung and chest wall. Symptoms are chest pain and difficult breathing.

Polio: An infection of the spinal cord with serious complications like muscle paralysis and inability to breathe. Practically eliminated from our country by the polio vaccine. Occasionally causes minor epidemics (but great suffering) in religious sects that forbid immunization.

Polydactyly: Extra fingers or toes present at birth. The extra digit is usually adjacent to the little finger or toe. Dominant type of inheritance giving a 50 percent rate in offspring. Surgical removal for cosmetic reasons is fairly simple.

Prematurity: Birth of a newborn weighing less than 2,500 grams (5 1/2 pounds). Occurs in 7 percent of births. A preterm baby is one born before 37 weeks of gestation. The smaller the baby, the higher the complication rate. Neonatal intensive care units have drastically improved survival rates and reduced complications.

Prognosis: A forecast of the probable course and outcome of a disease.

Pulmonary embolism: A blood clot carried through the blood stream to the lungs. Causes severe chest pain and difficult breathing.

Pyelonephritis: A kidney infection.

Pyloric stenosis: An obstruction of the stomach outlet occurring in the first 4 to 8 weeks of life. Causes projectile vomiting and requires surgery.

Recurrent abdominal pains (RAP): Recurrent stomachaches occur in 10 percent of children. While the causes are legion, over 90 percent are on a nonphysical basis.

Retrolental fibroplasia or Retinopathy of prematurity: Damage to the retina that occurs in small prematures (less than 1,500 grams) with high oxygen therapy requirements. The name comes from overgrowth of fibrous tissue behind the lens. The result is reduced vision or blindness.

Rett syndrome: A type of mental retardation that only occurs in girls. These children start out normal but lose intellectual and motor function between 6 and 18 months of age. The most characteristic symptom is repeated wringing of the hands.

Reyes syndrome: Abrupt swelling of the brain presenting with confusion, sleepiness, and persistent vomiting. Liver destruction also occurs. Although the cause is unknown, it sometimes follows chicken pox or influenza. Also associated with aspirin ingestion during these illnesses.

Rheumatic fever: A rare complication of an untreated strep throat. The symptoms are migrating joint pains and fever. The heart is involved over half the time and can sustain permanent damage of the valves.

Rheumatoid arthritis: An arthritis that usually involves large joints on both sides of the body. Morning stiffness is common. Joint damage is occasionally seen.

Rocky Mountain spotted fever: A life-threatening disease caused by a rickettsia that is carried by ticks. The symptoms include a purple-red rash of the extremities, fever, headache, and delirium. It responds to antibiotics.

Scabies: A very itchy skin rash consisting of small red bumps, pimples, and tunnels. Caused by a mite (small insect) that burrows under the skin to lay eggs. Very contagious.

Scalded skin syndrome: A bright-red, painful rash in which the skin peels off in sheets like a burn. The rash is caused by a toxin released by staph bacteria, often residing in the nose. The outcome is good.

Scoliosis: A sideways curving of the spine. Usually begins at age 10. Predominantly in girls. Screened for in most schools. Bracing is needed if the curve exceeds 20 degrees.

Septicemia: A bacterial infection of the bloodstream in which the bacteria are actually multiplying there.

Sequela: A pathologic condition that follows as a consequence of a disease.

Serous otitis media: Fluid in the middle ear due to blocked eustachian tubes. A problem of young children, sometimes requiring the insertion of ventilation (tympanostomy) tubes for 1 or 2 years.

Sexually transmitted diseases: Infections of the male and female genital tracts. Also called venereal diseases. Chlamydia has passed gonorrhea as the most common organism.

Shigella: A bacterium that causes severe diarrhea, often bloody. Treatable with antibiotics.

Sickle cell anemia: An inherited type of anemia where the normally round red blood cells periodically become sickle-shaped and block off small blood vessels, causing severe pain. Also interferes with growth. Mainly occurs in Blacks at a frequency of 1 in 500.

Sickle cell trait: Children with sickle cell trait carry 1 gene for sickle cell anemia. It takes 2 genes to develop the disease. No symptoms or anemia. Present in 10 percent of Blacks.

Spider nevus: A blood-vessel abnormality of the skin which looks like a spider. When the red spot in the center is pressed with a pen, all the small radiating blood vessels or spokes disappear. Occurs normally from age 6 to 12 in 50 percent of children. Clears spontaneously with puberty. Rarely associated with liver disease.

Spina bifida: a birth defect of the spinal column and cord that causes paralysis below the level of involvement, as well as poor bladder-bowel control. Also called meningomyelocele. The cause is unknown.

Strabismus: a birth defect of the eye muscles causing crossed eyes (i.e., inward or outward turning of 1 or both eyes). Usually requires surgery. More than 90 percent of children suspected of having this actually have pseudostrabismus due to a broad nasal bridge or folds of tissue (epicanthal folds) over the inner parts of the eye. These decrease the visible sclera (white part) on the inside of the eyes and give an optical illusion of turning in.

Strawberry hemangioma: A raised bright-red benign tumor that begins in the first month, grows rapidly during the first year, then slowly shrinks down until it disappears at ages 5 to 10. Surgery is unnecessary.

Strep throat: A throat infection caused by streptococcus bacteria. Usually requires a throat culture for diagnosis. Responds to penicillin.

Striae: Stretch marks on the skin occurring in areas of rapid weight gain (e.g., the thighs), rapid muscle expansion (e.g., the shoulders of weight lifters), or on the abdomen during pregnancy. Usually temporary.

Subdural hematoma: A blood clot on the surface of the brain, usually due to direct trauma. Violently shaking a child by the shoulders so the head is snapped forward and back can also cause this life-threatening condition.

Subluxation of the radial head: A partial dislocation of one of the bones of the forearm (the radius) at the elbow. Due to being suddenly lifted or pulled by the hand. An infant with this injury will not use the arm and keeps the hand turned down. Easily remedied by your child's physician.

Sudden infant death syndrome (SIDS): The sudden unexplained death of a healthy infant under 12 months of age during sleep. The incidence is 2 in 1,000 live births. The cause remains unknown.

Tay-Sachs disease: An inherited disease in which the brain degenerates. Onset at 3 to 6 months of age. Findings are blindness, arrested development, and seizures. Mainly occurs in the East European Jews.

Testicular torsion: An unexplained twisting of a testicle that shuts off its blood supply and requires emergency surgical release. Presents with testicular pain and swelling.

Tetanus: A serious bacterial wound infection that progresses from local muscle spasms to total body rigidity and seizures. Preventable by DPT immunizations and tetanus boosters.

Thrombophlebitis: An infection of the lining of a vein, often the deep veins of the calf muscles.

Tonsillar abscess: An abscess deep within the tonsil that causes a severe throat, muffled voice, inability to open the mouth fully, and drooling. Requires surgical drainage.

Tourette's syndrome: Frequent facial muscle jerks (tics) and irrepressible sounds (such as grunting or profanity). Onset at 2 to 6 years of age. Inherited in 50 percent of cases.

Toxic shock syndrome: Symptoms include shock, fever, diarrhea, and a bright-pink (scarlet-fever like) rash. Caused by a toxin produced by a hidden staph infection. One common source of staph overgrowth is a tampon left in the vagina overnight.

Trench mouth: A bacterial infection causing red, swollen, ulcerated gums and bad breath. Responds to dental hygiene and antibiotics. Not contagious.

Trichinosis: A disease due to a small roundworm sometimes found in pork. Transmitted by undercooking the meat. The symptoms of fever, a swollen face, and muscle pains begin 1 week later.

Trichomonas: An amoebalike organism that can cause vaginal infections and discharge.

Tuberculosis: A bacterial disease of the lungs that can go on for years if not treated. Symptoms include cough, fever, and weight loss. Now rare in the United States except in immigrants.

Turner's syndrome: in females, a missing X chromosome (i.e., X instead of XX). Features include short stature, abnormal ovaries, lack of sexual development, and infertility. The intelligence is normal.

Typhoid fever: A severe form of bacterial diarrhea (often bloody) that can lead to a bloodstream infection or intestinal complications. Treatable with antibiotics.

Ulcerative colitis: Inflammation of the lining of the large bowel, which causes intermittent or continuous loose stools and cramps. Usually the stools contain mucus, pus, or blood.

Urethritis: An infection of the urethra, or tube that drains urine from the bladder to the body's surface.

Urinary tract infection (UTI): An infection of the bladder (cystitis) or kidneys (pyelonephritis).

Von Willebrand's disease: An inherited bleeding tendency due to problems with both platelets and clotting factor 8. Symptoms include severe nosebleeds, excessive menstrual flow, and increased bruising with trauma. Not as severe as hemophilia.

Wilson's disease: An inherited disease in which the liver can't excrete copper. The onset is after age 10, with jaundice, tremors, and deterioration in school performance.

COMMON MEDICAL ABBREVIATIONS

AIDS - Acute Immunodeficiency
ALS - Amyotrophic Lateral Sclerosis
AMA - American Medical Association
ARD - Acute Respiratory Distress
bid - Twice a day
BP - Blood Pressure
BR - Bed Rest
B.S. - Blood Sugar
BUN - Blood Urea Nitrogen
Bx - Biopsy
CA - Cancer
Ca - Calcium
CAB - Coronary Artery Bypass
cap - Capsule
cath - Catheter
CBC - Complete Blood Count
CCU - Coronary Care Unit
Chol - Cholesterol
CPR - Cardiopulmonary Resuscitation
CRNA - Certified Registered Nurse Anesthetist
CS - Cesarean Section
CT/CAT - Computerized Axial Tomographic Scan
CCA - Cerebrovascular Accident
DB - Diabetic
DBP - Diastolic Blood Pressure
D&C - Dilation and Curettage
DM - Diabetes Mellitus
DPT - Diphtheria, Pertussis, Tetanus
ECG or EKG - Electrocardiogram
EEG - Electroencephalogram
EENT - Eyes, Ears, Nose, Throat
ER - Emergency Room
FACS - Fellow American College of Surgeons
FDA - Federal Drug Administration
Fe - Iron
FHR - Fetal Heart Rate
FF - Forced Fluids
GB - Gallbladder
GI - Gastrointestinal
Glu - Glucose
GU - Genitourinary
HCFA - Health Care Financing Administration
htc - Hematocrit
HIV - Human Immunodeficiency Virus
hgb - Hemoglobin
HR - Heart Rate
ICN - Intensive Care Nursery
ICU - Intensive Care Unit
IM - Intramuscular
IUD - Intrauterine Device
IV - Intravenous
K - Potassium
LOS - Length of Stay
LPN - Licensed Practical Nurse
MD - Muscular Dystrophy
MG - Myasthenia Gravis
MI - Myocardial Infarction
MMR - Measles, Mumps, Rubella
MRI - Magnetic Resonance Imaging
nl - Normal
NPC - Nonproductive Cough
OB - Obstetrics
OBS - Organ Brain Syndrome
OD - Overdose
OM - Otitis Media
OR - Operating Room
O.T. - Occupational Therapy
OTC - Over The Counter
PA - Physician's Assistant
Pap - Papanicolaou
PC - After Meals
PE - Pulmonary Embolism
P.E. - Physical Examination
PG - Pregnant
PMS - Premenstrual Syndrome
prep - Prepare For
PRN - As Often As Needed
procto - Proctoscopy
P.T. - Physical Therapy
qd - Every Day
qh - Every Hour
qid - Four Times A Day
qod - Every Other Day
Rad - Radiology
RBC - Red Blood Count
rehab - Rehabilitation
RHD - Rheumatic Heart Disease
RN - Registered Nurse
RT - Respiratory Therapy
Rx - Prescription Therapy Treatment
SBP - Systolic Blood Pressure
SIDS - Sudden Infant Death Syndrome
staph - Staphylococcus
STD - Sexually Transmitted Disease
strep - Streptococcus
T - Temperature
T&A - Tonsillectomy and Adenoidectomy
trach - Tracheostomy
Trig - Triglycerides
TUR - Transurethral Resection
TURP - Transurethral Resection Of the Prostate
U.A. - Urinalysis
US - Ultrasound
UTI - Urinary Tract Infection
vas - vasectomy
vasc - Vascular
V.D. - Venereal Disease
VS - Vital Signs
W.B.C. - White Blood Count

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